

DYING CHILDREN AND THEIR FAMILIES :

A THERAPEUTIC APPROACH FOR CLINICAL PSYCHOLOGISTS

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FOR

Gawie de la Bat

Jaques de Villiers

Bokkie du Toit

Wouter Stander

and many others

Who were too young to die
But faced death courageously
And shared it with me.

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A B S T R A C T

The aim of this thesis is to describe the clinical psychologist's potential role as a member of the interdisciplinary team dealing with dying children and their families. For this purpose, it includes a theoretical review of the experience of the child who suffers from terminal illness, and the expected reactions of the family. The psychologist's contribution is described; the existing literature is reviewed and suggestions for possible further therapeutic intervention with the child and his family are made. It is concluded that the psychologist is a potentially valuable source of support for both the child and his family, someone who can improve the quality of the child's life and eventual death, and assist the family in their adjustment to the loss of a child and a sibling.

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CHAPTER 1

INTRODUCTION

There has been an unprecedented interest in the subject of death and dying since 1970, leading to a tremendous increase in publications on the subject. Despite this upsurge, research workers have paid little attention to dealing with dying children and their families.

Over past generations, death in infancy and childhood was frequently experienced and most families lost a member of the family at an early age. Children suffered from infectious disease, the onset of which was sudden and the course swift. Today, by contrast, advances in medical knowledge and improvements in nutrition and domestic hygiene have brought about a dramatic reduction in infant and child mortality. Whilst such progress is an obvious source of satisfaction, it is not without disadvantages. Chemo- and radiotherapy have extended the life expectancy of terminally ill children considerably, and the child with a terminal illness may feel different, lonely and unable to participate in or meet the requirements of an increasingly competitive and achievement orientated society. What is more, true illness may continue for years, with increasingly frequent relapses and even shorter periods of remission. This serves as a constant reminder of the diagnosis and the fatal prognosis.

In our death-denying society, where the primary emphasis is on youth, life and vitality, the terminal illness of a child has a considerable impact upon the family constellation. The majority of families are ill-prepared for the suffering and concrete problems which the crisis of a dying child creates. Parents of children who are diagnosed with terminal illness often experience the fact as incomprehensible and incredible. With the great reduction in the likelihood of death in infancy, childhood and young adulthood, and the general improvement in life expectancy, it has become increasingly probable that individuals will reach adulthood or even middle

age without personal experience of death in their families or intimate circle of friends, and they are therefore ill-prepared to cope emotionally with the tragedy of a dying child.

In an increasingly secular society, traditional sources of religious support are no longer so widely valued and as a result of greater geographical and social mobility, near relatives are not so readily available. Consequently, when death intrudes, previously existing emotional and institutional supports which cushioned its impact, are absent, and families faced with supporting a dying child are most often at a loss as to where to turn for help. The feeling of isolation is increased by the fact that the majority of children in our society die in hospitals and, as a result, both the child and his parents are deprived of the consolation which familiar things and people provide. This may lead to feelings of despair, helplessness and bewilderment.

It is important for everyone who is interested in and involved with the care of the dying child to understand what the child goes through emotionally and physically, and for this reason this thesis includes a review of the literature describing the experience of the dying child and the reactions of the family.

Developments within the medical world have been characterised by increasing specialisation which, in turn, has led to a need for co-ordinated care, to ensure that the patient be viewed and treated as a whole person. This has led to the development of a team approach to the patient. In working with dying patients, physicians may frequently feel inadequate, even resentful, and the patient may consequently be regarded as a personal failure. In such circumstances, physicians are often eager to engage other members of

the staff to contribute to the well-being of the patient, until the moment of dying and death.

The responsibility of caring for the dying patient requires special skills and an unique approach to such patients is required of members of the interdisciplinary team. However, when the patient is a child, this often becomes an arduous, draining and demanding task. The death of a child is seen as one of the outrages of nature, an exceptional and tragic waste because the basic efforts of childhood are traditionally expected to be directed towards completing development by achieving increased emotional and physical control over the self and the environment. When a child has a terminal illness, instead of achievement and growth there is deterioration and death.

The clinical psychologist has earned his place and has been accepted as a full and respected member of the team in the general medical context, and he contributes significantly to the welfare of the patient by assessing cognitive, personality, behavioural and other characteristics of the individual. Through psychotherapeutic intervention he may assist patients to understand themselves better and to make better adjustments to their illness and the trauma of resulting incapacity. The patients generally referred to the psychologist are those who have a good prognosis, or those whose intellectual functioning must be assessed after brain injury. It is remarkable that, in the existing literature, clinical psychologists are seldom included as being important to the care of the dying patient. It seems that the terminally ill patient, whether adult or child, has not been regarded as falling within the range of the psychologist's expertise. For this reason, this thesis intends to illustrate that the clinical psychologist may play a very important role, if not an indispensable one,

in the interdisciplinary team which is responsible for the care of the dying child.

The second chapter is concerned with the development of the child's concept of death, which is important in understanding the child's ability to conceptualise death at different stages of development. The physical, emotional, social and spiritual world of the dying child is described in Chapter 3. The clinical psychologist's role in assisting the dying child to cope with impending death, and all it entails, is the central topic of Chapter 4. The problems, as experienced by the family as a whole, by subsystems within the family, and by the individual family members are the focus of Chapter 5, while Chapter 6 illuminates, once again, the important role of the clinical psychologist in caring for the family, and suggests methods of therapeutic intervention (Burton, 1975; Boyd, 1977).

CHAPTER 2

THE DEVELOPMENT OF THE CONCEPT OF DEATH IN CHILDHOOD

2.1 INTRODUCTION

One of the many problems in dealing with children and death, or with the dying child, is the tendency of adults to equate their perceptions of death with the child's perceptions. In this way, adults either deny the fact that children are able to experience the reality of death and loss, and pretend that childhood is joyful without any sorrow, or they approach children from a position of emotional and intellectual superiority, making communication impossible.

If adults want to help the child cope with death, it is essential that they know something of the child's world of thoughts and feelings. Furthermore, it is important to understand that children differ in their ability to comprehend and cope with death. It must be realised and acknowledged that the development of the concept of death is a gradual process, which is influenced by many factors within the child's cultural and familial environment, as well as by his own unique psychological and cognitive patterns (Hostler, 1978).

In order to understand what "death" means to a child, and to be able to determine how a particular child will interpret death, Kastenbaum (1977) stresses the fact that access to the following information is of crucial significance:

- (a) The child's development level: Individual rates of maturation vary considerably and chronological age is only an approximate guide to the level of developmental functioning that has been achieved. Developmental levels are an important consideration,

because they tend to establish the limits within which the child can comprehend any phenomena, whether or not related to death.

- (b) The child's personality: The contribution of the individual personality to the child's interpretation of death is important. Whatever it is that makes a particular child distinctive or unique will also influence his way of interpreting death-related phenomena.
- (c) The child's life experiences: Life experiences, such as death of a parent, prolonged separation, frequent changes of neighbourhood by the family, illness, etc., can sensitise a child to death-related phenomena in various ways.
- (d) The child's support and ability to communicate: How a child interprets death is also related to the general pattern of communication which has been established, especially with parents. The child from a family where openness and honesty characterise their communication is more likely to talk about death-related thoughts and feelings in crisis situations.

Furman (1964) contends that:

"Applied to the ability to master the concept of death, the necessary levels of reality principle acceptance and of reality testing would require: (1) Sufficiently stable and differentiated self and object representations in the inner world so that the integrity of the self representation can withstand the threat implicit in the death of someone else; (2) sufficient ego mastery over the id so that the concept of death can be relatively more integrated within the ego's expanding pool of knowledge, rather than utilized for the arousal of instinctual derivatives; (3) the ability to distinguish animate from inanimate and thus have a concept of the living as opposed to the nonliving; (4) some ability to understand time in terms of the past, present and future; and (5) sufficient secondary-process causal thinking to understand that since something is dead, it can no longer do certain things."

The development and understanding of death is best viewed in the broader context of the child's general intellectual development. The developmental psychologist, Jean Piaget (1973), has provided the most comprehensive and widely recognised description of cognitive development from infancy to adulthood, and it is reasonable to expect that cognitions of death develop in the same way and follow similar principles, as do other cognitions.

The gradual accumulation of information, which becomes the child's concept of death, is a developmental process which coincides with his maturational process. For this reason, I will examine and discuss the concept of death in four developmental periods:

1. The infant and the toddler (0-3 years)
2. The pre-school child (3-6 years)
3. The early school-aged child (6-10 years)
4. The pre-adolescent and adolescent (10-20 years)

There are, however, as in other aspects of development, individual differences in rates of development, and the division into four stages is arbitrary since the grouping is neither fixed nor precise. Schowalter, (1970, p. 52) warns:

".... these attitudes and concepts do not change abruptly at a given age, but evolve gradually and with wide individual variation."

2.2 THE INFANT AND THE TODDLER (0-3 YEARS)

During the first months following birth, the infant does not experience himself as separate from the world around him. He is totally dependent

upon someone else (usually his mother) for nurturance and survival. How these needs are met will be reflected in his ability to learn to trust that his needs will consistently be considered, which nucleus of trust will, in turn, begin to develop the infant's capacity to trust in his own inner feelings and functions. Erikson (1963) regards it of utmost importance that a sense of basic trust be established during infancy.

The infant comes to have a sense of being and non-being as he wavers back and forth between wakefulness and sleep. By the time he is three months old, the healthy baby is secure enough in his self to be ready to experiment with these contrasting states. A very common game among young children is "Peek-a-boo", in which the infant's face is alternatively covered and uncovered with a light cloth. In this game, the infant replays, in safe circumstances, alternate terror and delight, confirming his sense of self and risking and regaining complete consciousness.

To the empathetic observer, it is obvious that the infant enjoys the temporary dimming of light, the blotting out of the reassuring face of mother or anyone else, and the suggestion of a lack of air which his own efforts (short, sharp intakes of breath and vigorous thrashing of arms and legs) enable him to restore. The fearful expectancy and explosive relief while playing "peek-a-boo" show how real the anxiety is at possible loss. On the other hand, his aliveness is confirmed by the happy greeting and the recognition implicit in the eye-to-eye oneness with another human being. It is interesting that, etymologically, "peek-a-boo" stems from old English words which mean "alive or dead?" Awareness of being and of non-being is thus the first of the series of adaptations to the fact of finite life (Maurer, 1966).

Once a baby becomes aware of the existence of other people as individuals,

distinct from himself, and distinct from objects which feed and comfort him, he begins to be aware of loss, of a sense of absence. His idea of time is limited and he cannot distinguish between short term separation and long term separation. However, the realities of disappearance and reappearance are quickly learned. Babies, a few months older, begin to delight in disappearance and return games. Overboard goes a toy, somebody fetches it, then overboard it goes again. The questions: "when is something gone?" and "when is something gone for ever?" seem very important to a child of this age (Kastenbaum, 1972).

But all things do not return. By one year, most children understand the phrase "all gone" and learn to say it. When the plug is pulled, bathwater becomes "all gone", and rare is the child who does not fear, at least at first, that he will go down with it. Faeces disappear down the plumbing, and the child wonders what happened to them. When the child begins to suspect that all things do not return, he attempts mastery of his fears of disappearance in another way. He learns to project "all gone" and to produce it at will.

Children seem to learn very quickly to distinguish a long separation from a short one, and by the end of the first year or so, a child has often learnt to tolerate short separations with relative equanimity. At this age too, a child faced with a long term separation of a person to whom he is attached, seems to experience at least some of the features of grief and mourning shown by adults, though without the depth which memories and expectations bring (Yudkin, 1968). Should loss occur, the child does not automatically transfer emotional attachment for his mother to someone else. Loss can constitute a considerable a shock to a young child because he has no innate notion that life ever ceases (Davidson, 1975). He does not contemplate his

own death and he sees no connection between either chance or a natural happening and death (Miller, 1973).

As the child becomes more mobile and develops into the next phase of psychosocial maturation (Erikson, 1963), he will become more autonomous. Often the first direct contact with death may be with dead flies, ants or worms, in and around the home. It may even be with a pet or an animal in the yard. These experiences teach him that death has definite characteristics, such as not breathing, not moving, being still and cold. Parents may use the word "dead" to confirm his observations. There is often much curiosity about death, focussing upon what becomes of the body and why a dead person is buried, etc. The dead are regarded as "less alive", not entirely devoid of sensation and functioning. The toddler thinks about death, but is unable to conceptualise it because his thinking is still, in terms of Piaget's (1969) categories, pre-operational. The toddler cannot distinguish between fact and fantasy. He cannot see connections between events and, therefore, he distorts much of what he is told. He usually thinks of death as something which happens to an adult (Miller, 1973).

Jackson (1977) emphasises the fact that the toddler has limited language facility. The capacity to remember seems closely related to the ability to use verbal forms. Also, the toddler's life is very much centred in the "now" because of his feelings of need and relationships. Thus, the concept of death, which includes time and space ideas, has not yet been developed. In order to think of death, a person needs to be able to think in terms of finality or some terminal event. However, there are differences of opinion here. Stern (1977), for example, feels that the pre-occupation with death starts early in life and quotes Anna Freud (1960), who thinks that the child at the age of two or three already has some idea of death and, at the

age of three and a half or four, is able to mourn.

It has not been firmly established exactly when children become aware of death, but the majority of theorists seem to agree that the child develops the capacity of perception and perceptual differentiation during this stage. These are precursors of thinking, but there is no actual conceptualisation, so infants have no concept of death. They are capable of forming internal images, but these images are of objects found in the infant's immediate world, such as people, food and toys (Wass, 1982).

2.3 THE PRESCHOOL CHILD (3-6 YEARS)

The preschool period in a child's life approximately covers Stage III of Erikson's theory of development (1963). The central issue during this stage is initiative. During these years the child is a "bundle of energy". He spends his time refining skills and motor activities which were learned during earlier stages, initiating new ones, and increasing and initiating mental activities also. This period is a critical time, in which he is ready to learn quickly and avidly to become co-operative - joining with other children in order to plan and construct.

The pre-school child acquires a specific sense of himself. The capacity to think, reflect and inquire, begins to emerge. He acquires a sense of self control and self direction. He develops the ability to communicate with others and learns to understand what others are communicating to him. His command of language becomes rather impressive. This development of language skills alerts us to the fact that the child's mind is now acquiring some freedom, range and versatility. It becomes evident that

even the three year old has begun to enjoy the "world of ideas", and we expect the child both to think more about death and related topics, and to share his views with adults. Curiosity is one of the young child's strongest traits. It is important to the child that he gains some understanding of his origins and destination, birth and death. "Where was I before I was? Is it possible that I might go back there again?" These questions hold meaning for a child, and they are often asked. The child tries to relate words and events to the language which he is discovering (Kastenbaum, 1967; Kastenbaum & Aisenberg, 1972; Anthony, 1973; Kavanaugh, 1974).

The pre-school child is active in exploring the world, but he is still the centre of much of this outward activity and is strangely preoccupied with himself and his body, wanting to know how it works and feels. His concern with death has biological dimensions for he is trying to build a concept of death which fits biologically into his growing ideas of both life and death. He will now begin to investigate dead things like birds and cats, worms and frogs, and will try to discover the difference between life and death. Some of the questions asked may seem inappropriate: "How do you eat when you are dead?", or "How do you go to the bathroom when you are dead?" These have been important concerns in life and he now tries to relate them to the concept of death. He may show that he knows a person is dead and buried, but he still may not be clear as to the nature of sensory processes. He may ask: "If I yell loud enough can Grandma hear me?", or "If I jump on her grave will it hurt her?" (Jackson, 1977).

The pre-school child also refines the concepts of social and physical realities in culturally directed ways. He learns appropriate ways in which to relate emotionally to others, particularly to his parents, and comes

to terms with the social values which will influence his later development (Lonetto, 1980).

As the horizon of the child's world widens and he forms associations with others, he begins to understand that death is something which happens to other people and, although he may have had some first-hand experience with the death of a flower, an animal or a relative, the concept is still vague, associated with sleep and the absence of light or movement. The words "sleep" and "rest" are often used by parents and adults when they talk about death, and children of this age group who overhear this may become fearful and unwilling to go to bed at night (Anthony, 1973). They may be liable to have nightmares, fears and phobias. However, these disturbances are usually transient, minimally disturbing and pass without any great lasting effect. Even though the child knows and speaks the words "dead" and "died", he still understands them as referring to a reversible event, a temporary restriction, loss of mobility, or departure. But compared with the toddler, he is better able to withstand and understand short separations. Life may be attributed to anything that moves, or even anything that is useful. Death, then, is understood as the opposite of life, and is often described as dark, remote and constricted (Schowalter, 1970).

During this stage, the child also becomes aware of his unique self to an increasing extent. To become aware that one is a separate, distinct individual in this big and powerful world may provoke anxiety. Even more terrifying is the knowledge which gradually dawns on the child that the unique physical being, called "me" - separate, distinct and able to make decisions - will somehow cease to be - that "Me" will become "not-me". The capacity to think, reflect and to inquire, begins to emerge and he acquires

a sense of self-control and self-direction (Easson, 1976). Maria Nagy (1959), who conducted pioneering work in this field, studying Hungarian children in the late 1940s, reported that children in this age group attribute life processes and consciousness to the dead. The deceased continues to live in the confines of the coffin, where he breathes, eats and knows what is going on in the world outside. Rochlin (1967) corroborates Nagy's findings, suggesting that children of this age group find death reversible. They believe that when someone dies, they continue to grow, to get hungry and eat. Excremental functions, as well as locomotion, continue. Children attribute life to everything. There is no such thing as lifelessness. Nagy (1959) stresses the fact that the most painful experience at this age is separation.

By now the child knows he is a separate physical entity but, as stated above, he can only understand events from the narrow perspective of his own experiences. Wass (1982) emphasises four ways of reasoning in children of this age group, which are considered important:

- (a) Animistic thinking: The child believes that the whole world and everything in it is alive. Life is attributed to sun, moon, clouds, rivers, stones, cars, etc.
- (b) Magical thinking implies that everyone can make everyone else do things, and that even objects have this kind of power. People and objects can give orders but they must also obey. With this kind of causal thinking, anything is possible. Mountains open up when you tell them to do so, flowers talk, birds tell you secrets, etc.
- (c) Artificialistic thinking is the belief that everything is manufac-

tured for people's convenience. Daylight can be turned on so that people can see, etc. This kind of reasoning explains why young children frequently assume that dead animals can be fixed, like toys or other objects.

- (d) Psychological causality refers to the child's tendency to perceive a personal motive as the cause of certain events, for example, children believe that bad dreams are sent to them because they have been bad.

At this stage the child not only learns facts, and experiences social attitudes about death, but also has many fantasies. Fantasy mingles with facts and with adult attitudes, and this often adds terror to the fantasy. A child of this age knows what it is like to hold his breath and he knows what it is like to be alone. He can imagine what it might be like to be put into a box deep in the ground. To be dead might be to wake up and find you are in a box under the ground, unable to breathe when you are bursting with holding your breath. It might mean being alone for ever (Yudkin, 1968). Fantasy is often used by the child as an attempt to maintain some control over feared events, through the control of mental imagery.

The child of this age socialises and is involved in games. Play represents an additional form of mastery over fear, through fantasy. Anthony (1973) felt that, in moderation, children's anxiety about death is not only normal but inevitable, and could explain their use of "magic" as a way of coping with feelings of this kind.

Many games popular at this stage are related to death. For example, "Ring-around-the-rosy" is a delightful game which arose during the bubonic plague in medieval Europe. Joining hands was the ritual of life, but in

the ritual of movement, suddenly "all fall down". This was a realistic playing at death, with the fortunate consequence that all could rise again. "Cowboys and Indians" is a game in which, after the "bang, you're dead", everything returns to normal. Death is not permanent, but more like temporary banishment (Kastenbaum, 1972).

In the Bellville area, the latest game which children play is "Virus-virus". This is apparently related to the outbreak of the fatal disease, "Congo Fever". One of the children is contaminated with the deadly virus. The other children run away to avoid the fever and certain death. Everyone touched by the "infected" child becomes ill and dies, and is then excluded from the game. The winner is the longest surviving member of the group.

A certain number of nursery rhymes deal with death, often murder:

"Who killed Cock Robin?"
 "I", said the Sparrow
 "With my bow and arrow,
 I killed Cock Robin."

An African lullaby reads:

"Twist his neck, and hit him on the head
 Throw him in the ditch and he'll be dead."

Many children learn the prayer:

"Now I lay me down to sleep,
 I pray thee, Lord, my soul to keep.
 If I should die before I wake,
 I pray thee, Lord, my soul to take."

This prayer connects death and sleep, which is a common enough association, as stated before. If the child, for some reason, already has some anxiety about either death or the dark, this prayer is hardly reassuring. In fact, the prayer may frighten and prevent him from falling asleep.

As we have seen, the pre-school child discovers death as part of the world around him. When he does observe death, it is a puzzle that he often solves with a magical prelogical explanation. In conclusion, the results of various studies show that at this stage children have erroneous or incomplete understandings of death, which is conceived as a reversible event such as sleep, a departure, or as a temporary state of restraint and deprivation.

2.4 THE EARLY SCHOOL AGED CHILD (6-10 YEARS)

This period almost completely overlaps with Erikson's (1963) Stage 4 and begins with the child's entrance into the expanded social and industrial world of the classroom, where he begins to use and test all that he has learnt in the seclusion of his family and immediate neighbourhood. The tasks during this stage concern settling and fitting in, especially in relation to physical development. The social development of the child is influenced by the pressures of his peer group. Ideas about the self and events in the world are expressed, exchanged and assessed. The child is now able to employ the rules of logical inquiry and is said to be in the phase of concrete operations (Piaget, 1969). This concrete operational period is marked by more mobility in thinking, because of the transition from static to dynamic, centration to decentration, and irreversibility to reversibility.

These early school years coincide with Nagy's (1959) Stage II, in which children generally personify and externalise death. Fifteen per cent of the children in Nagy's study said that they thought about death in the

evening, and that it was usual to die at night. Personifications not only made death visible but also humanlike in appearance. This visibility may span only a brief time before death carries a person off. If one acts quickly, there may be just enough time to out-manoeuvre death. For example, the imagination can picture death as a ferocious animal in human form, which surprises one in the dark. Death is frightening, disturbing, dangerous, unfeeling, unhearing and selective. Death may be imagined to be invisible like a ghost, or ugly like a monster, or it may be a skeleton. Death can be an actual person or the companion of the devil, a bringer of illness or an angel. Initially, as children personalise death, they see it as a temporary departure but, eventually, they begin to see it as final, as a permanent separation. Friends leave school or the neighbourhood, never to return. Dogs die and the neighbours buy a new puppy (Kavanaugh, 1974). Death is now experienced and accepted as a reality, but the child still sees it as outside himself and, as yet, not universal. Death is believed to happen to old people and certainly not to young people. Although they often flirt with the idea of death through stories, games and riddles which make their spine tingle, children in this stage do not really like to think about it. They see death as remote and want to keep it that way.

Although Kübler-Ross (1969) writes of the "bogey-man and death man who takes people away", and Maurer (1966) describes the child's personification of death as a necessary defence against fear, recent studies have not observed children's use of personification (Koocher, 1974; McIntire, Angel & Struempfer, 1972). It has been suggested that its omission may be a result of cultural differences, religious education, or different coping styles of the children studied (Hostler, 1978).

Nagy's sample (1959) in this age group included some children who regard

death as a contingency for bad deeds, demonstrating their persistent egocentrism and magical thinking. The child begins to seek explanations with an increasing belief in spiritual immortality (Kastenbaum, 1967; Schowalter, 1970).

McIntyre, Angel & Struempler (1972) found that belief in personal or universal spiritual continuation after death ranged from 20% in Jewish children to 65% in Catholic children. Wass (1982, p. 83) states:

"Death is understood as an irreversible event. The only possibilities for returning to life are through reincarnation or resurrection, and these are matters of one's beliefs. At this stage, children still list external forces such as violence, accidents, or disaster as causes of death, but more frequently they describe internal causes, such as illness and old age, or give physiological definitions, such as cessation of vital functions or laws of nature. At this stage children are intensely interested in the physiological aspects of death. Regardless of religious affiliation, they are preoccupied with decomposition and decay."

It must be pointed out that the conceptualisations of children in this age group also reflect their socio-economic background. The inner-city population stated aggressive causes of death, such as accidents, violence, war and suicide, four times as frequently as the suburban church school pupils of the same age, although television watching habits of the two groups were reported as similar (McIntyre, Angel & Struempler, 1972).

In a study conducted by Kane (1975) and quoted by Lonetto (1980), it was concluded that by the age of seven, children acquire ideas about death similar to those commonly held by adults. It was also noted that by the age of six the child has added to his death concept the components of causality, dysfunctionality, universality and irrevocability. To the children in Kane's study, death was a feature of old age and, therefore, very far away. Lonetto (1980) also quotes Childers & Wimmer (1971), who

found in their study that after the age of nine, children understand the universality of death, but as yet have not extended their reasoning to include the idea of the irrevocability of death. By ten years of age, most children seem to have completed a transition in both mental development and emotional security. They now express an understanding of death as a final and inevitable universal outcome of life: "Death is the end of life on earth"; "Death is something you cannot escape".

The work of Piaget (1969), Anthony (1973) and Gesell, Ilg & Ames (1977) suggests that as the child approaches adolescence he, is equipped with most of the intellectual tools necessary to understand both life and death in a logical manner. The conceptualisation of time, space, quantity and causality has now been completed, and the world is a more comprehensible and predictable place. This gives him a framework within which the idea of death can be placed. Death is one general principle or process amongst many other general principles or processes, and by this age, children have had sufficient experience in learning what it means to be alive, and can appreciate and understand not being alive (Kastenbaum, 1967; Cook, 1974).

2.5 PRE-ADOLESCENCE AND ADOLESCENCE (10-20 YEARS)

Erikson (1963) describes the crisis which confronts the child at this point in life as being that of Identity versus Role Confusion. The child's task at this juncture is to organise his knowledge about himself and his relationship with his social world into an integrated whole, so that he is able to cope with what stretches before him, his future. The integration now taking place is that of ego identity, which is the accrued experiential information about himself which he has gained from childhood identifica-

tions. Along with his struggle to determine his ego identity, the adolescent also wrestles with the problem of occupational identity - presupposing a future which must now be considered with all its possibilities. Along with drastic bodily changes, he is flooded with sexual feelings which engulf his body and imagination with all sorts of impulses. The task of integrating his ego identity is an enormous and frightening one, even under the best of circumstances. Rapid transformations are being experienced in every sphere: physical, social, emotional and cognitive.

Piaget (1969, 1973) has had surprisingly little to say about the child's conceptualisation of death, but his general view of mental development would seem to suggest an even later age range for the cognitive grasp of death's finality. Piaget's theory distinguishes a level of "abstract operations", which does not become well established until early adolescence, or thereabouts. Until the person has developed these high-level mental processes, it is possible that he cannot fully realise the finality and inevitability of death (Kastenbaum, 1977).

Death is now understood, not only as final, but inevitable and universal. The child finally realises that mortality is a condition of life throughout the plant and animal kingdoms, and one's own self and loved ones are not exempted. The adolescent can think symbolically, being able to philosophise, daydream, plan, criticise and imagine, and able to use quick abstract forms of thought and language. The adolescent's concept of death approximates to that of an adult (Schowalter, 1970).

"I will die", can now be said by the adolescent. Death is universal and he, as a member of the human race, is not excluded, so that in contempla-

ting his future, he knows it contains his own personal death. Death becomes the final separation, the ultimate separation, of the dying one from his world. Thus death is the cessation of corporeal life, and inevitable.

Erikson (1963) exhaustively describes the importance of the adolescent attaining an identity, questioning his values and life style and seeking to define the person he wants to be. It is a time of intense intellectual and emotional pre-occupation with the self, and a time to grasp oneself firmly and to say, "I am". To then become aware that one is going to die triggers what Solnit & Green (1959) have described as one of man's deepest fears - death before fulfilment. For adolescents, death means not only that there is nothing in their future, but that time spent in growing up has been wasted (Schowalter, 1970). Death represents the possibility of untimely curtailment of their freedom and the possibility of premature extinction. They are now sure that death is not only inevitable but unpredictable, which is worse. Whilst they may have outgrown most of their beliefs in magic, they may still be frightened of the possibility that something they may or may not have done may bring about death. It is common for adolescents to invest in the belief of some sort of spiritual continuation after death, but they are inclined to examine propositions very critically.

It is important to remember that there are differences among adolescents in their death-related thoughts and attitudes. Personality and life style differences are important here, as they were in childhood. Personality and sex differences are both influenced by cultural and subcultural patterns, and it is not necessary for a cultural pattern to be intrinsically death-

oriented for it to exercise an effect upon the individual's perception of mortality (Kastenbaum, 1977).

However, when the adolescent structures his life, death stands outside the mainstream. He may see it as a future threat, but it does not emerge as a part of his overall way of thinking. He lives intensely in the present - in an intense "now". Everything which he values and is important to him is contained in this "now", or in the immediate future, and the present is so real that his past and future are dim by comparison. It is normal for adolescents to have a sense of invulnerability, in spite of friends who are killed in accidents, in spite of cancer, and in spite of the reality of death in the armed forces (Miller, 1973). If death does get close to them and they become anxious, they try to cover it up by assuming airs of bravado. It is at this age that they make up jokes about death, and sing:

"When I die, don't bury me at all, just pickle my bones in alcohol." (Fredlund, 1976).

If the adolescent has a backlog of death anxiety which has been instilled in earlier years, this may be the time when this anxiety is acted out in irrational and often life-threatening behaviour, in which the adolescent attempts to master his anxiety by trying to prove to himself that he is not really afraid of death. Thus he may risk his life in order to allay his fears, and to prove that death cannot "get" him. Often this proves to be a tragic form of behaviour - reckless driving of a car, or destructive use of drugs, with devastating consequences (Jackson, 1977).

2.6 CONCLUSION

It can be said that this is still a rather defensive age, because of the tendency to view our children as being unaware of death in any form.

Although limited research has been done in this area, from what is available the message is clear: children do know, and are aware of loss and death all about them.

Nagy (1959) found that children questioned about death were spontaneous and willing and eager to talk. Children welcomed the opportunity to talk about death and dying, at their own level. Once children have gained some understanding of death, they do not generally try to evade the subject. The need to find answers to questions about death is amusingly illustrated in a letter published in the Saturday Evening Post of November 19, 1961:

Dear God,

What is it like when you die? Nobody will tell me. I just want to know. I don't want to do it.

Your friend
Mike.

If children express such needs and, when given the opportunity, do not deliberately avoid talking about death, then the problem lies with adults who frequently impose restrictions on discussing death and set up defences to protect themselves from their own fears. They seem to have great difficulty in accepting death as a part of life, and this is projected on to their children. This is regrettable, because children should be able to explore the idea of death within the warm and loving surrounds of his own family.

Studies conducted over a number of years confirm that cognitions of death develop in the same way and follow the same principles as do other cognitions. There are, however, as in other aspects of development, individual differences in the ages at which children reach these stages.

These differences may be maturational, or they may reflect differences in children's environment or life circumstances which, in turn lead differences in experiences (Wass, 1982). The child's awareness of death seems to develop from infancy, when the infant comes to have a sense of being and non-being, begins to experience disappearance and return, and gradually becomes able to differentiate between long and short separations.

During the pre-school years, he starts to use the word "dead", but sees death as a reversible event, a temporary restriction, a loss of mobility or a departure. During the school aged years, death is generally personified and externalised, but comes to be seen as final and as a permanent separation. During adolescence, death is finally seen as universal, permanent and inevitable. The adolescent thinks in abstract terms and in contemplating his future, knows it contains his personal death.

CHAPTER 3

THE EXPERIENCE OF DYING IN CHILDREN AND ADOLESCENTS

3.1 INTRODUCTION

The development of the concept of death, which coincides with the normal development of the child has been discussed in the preceding chapter. It must be stressed that this process is lengthy and difficult, under normal circumstances, with numerous pitfalls and obstacles. Every child needs support and encouragement from his parents and the environment if he is to master the numerous mental, physical, social, and emotional skills necessary to survive in this world.

When a child becomes ill, normal development is often affected, but when a child is diagnosed as terminally ill, this process becomes complicated and the majority of children find it extremely difficult to cope with the consequent drastic changes in their lives. Illness frequently brings about loss or curtailment of independence, unfamiliarity, anonymity, loneliness, boredom and pain. It affects strivings for self-expression and emotional development and is resented and feared (Burton, 1974 a). A secure and safe world ceases to exist and is replaced by a new environment, filled with procedures, laboratory results, radiological reports and medication. Hospitalisation becomes inevitable. The child's developmental milestones and personal needs are often forgotten in the process of providing the physical care necessary to sustain even a limited life expectancy. Health care providers may become so involved in life-saving measures, protocols and education, that the individuality of the child and family is lost in the shuffle. Children perceive what is happening on a feeling level: mother, father, sister, brother, relatives and friends and, possibly, even the staff appear to be afraid both of them and for them. Their parents are suddenly protective to the point of smothering. Regression, temper tantrums, or various other forms of misbehaviour may all of a sudden not

only be allowed, but even encouraged (Gyulay, 1978).

Burton (1975) suggests that the child's reactions to these changes may be influenced by age, level of development, nature of the symptoms, the degree of pain sustained, and alterations in life style necessitated by the disease and the manner in which others view the illness and alter their behaviour towards, and expectations of, the child (Schowalter, 1970).

Easson (1970) contends that social and cultural factors play a very large part in developing the child's appreciation and understanding of the diagnosis. Furthermore, the understanding of disease diagnosis is a function of the child's intellectual growth and training. The three year old girl, who has no real understanding of the meaning of the diagnosis of leukemia, can run gaily to her visiting parents, proclaiming loudly and happily: "Mommy, I got leukemia and a new dress".

3.2 THE CHILD AND THE TRUTH ABOUT THE ILLNESS

In dealing with the dying child, the question regarding open communication about the illness, the diagnosis and the prognosis always arises. There has been a historical development of attitudes whether a child should be told or not. In this section, different viewpoints will be discussed and research will be quoted to substantiate current thinking.

According to Waechter (1984), physicians in the 1950s and 1960s suggested that dealing with death prematurely in young children would be harmful and parents were counselled to shield children from the seriousness of their illness, pretending that things would soon be well.

Toch (1964, p. 422) states clearly:

"I strongly advise parents of older children to keep the fact that their child has cancer to themselves."

Evans & Edin (1968) suggest that what the child is told about the illness should depend on the child's age and ability to understand, and encourages the use of euphemisms and a "positive" approach by the physician. Verwoerd (1966) encourages parents to openly share their feelings and concerns, in order to gain support from each other, but suggests that this not be done in the presence of the children.

According to a study by Morrissey (1963), children's emotional problems, and especially anxiety, are related to, or associated with, their illness. Therefore, it was emphasised that the dying child could be helped to cope with his illness and approaching death by being shielded from any knowledge about the illness, and the maintenance of a "normal" family life.

"The happiest survivals I have seen were in children where the family was able to treat them as if nothing had happened, where the parents made their adjustment to their child's disease, tucked it away in the back of their minds and then went on living" (Toch, 1964, p. 421).

Bird (1973) emphasised the fact that the impact of the death of their child on parents is often so great that they are compelled to protect their emotions by attempting to disbelieve their child is going to die. He quotes an example of a ten year old boy, who was slowly dying and who, as the weeks went by, became increasingly apprehensive and disturbed about his deteriorating condition. He began asking his parents, his pediatrician and everyone else, if he was going to die; where he would go if he died; why he had to die, and why no-one could help him. His parents and his doctor, in their distress and compassion, did everything they could think of to calm and reassure him. They told him over and over again that he was doing all

right, would soon begin to improve, and would not die. When he continued to talk of dying, they scolded him for being morbid, for upsetting them, and for not believing them. The parents tried to keep busy and active and tried to do as much as they could for their son. They tried to think of foods he would like to eat, music he would like to hear, books to read, games to play. Everything they did for him was urgent and done with trumped-up enthusiasm and desperate hope, as if they were driven to find something that would do him good. The parents' denial is understandable and yet it resulted in the total emotional isolation of their son, throwing the burden of dying solely upon the child himself.

Tropauer, Franz & Dilgard (1977) found that about one-third of the mothers reported that their children had voiced concern about dying prematurely. As a result, parents attempted to reassure their children, which, at times, had questionable value. These attempts to protect children from the reality of their illness, with evasiveness and dishonesty, were challenged by a number of professionals. Several expressed concern about the fears, fantasies and isolation experienced by such children when their diagnosis and prognosis were treated as taboo. Burton (1974 a) pointed out that, as a result, the child becomes mute, outwardly accepting the adults' benign words of falsehood, but inwardly feeling abandoned. The child is left to cope with his fears and anxieties by himself at the very time when he needs and seeks all the strength and support available. Children in such circumstances rarely ask what is going to happen to them. This is not because they do not know or are uninterested, but more probably because the child knows it is a forbidden subject or is fearful of the answer.

Although children may not understand the full implications of their illness and the therapeutic interventions aimed at relieving distressing symptoms,

they are sensitive to messages, cues and signals from the people around them. They are quick to sense tension and anxiety in the family when bad news (i.e. the diagnosis of terminal illness) is received and quickly recognise that whatever is wrong with them is serious and "bad", having a profound effect upon their family and the medical staff attending to their needs. Even if their illness is not discussed at all, they sense through their parents' attitudes and behaviour that something serious is wrong. They may quite suddenly receive more attention, more toys, and their parents may look worried and concerned (Strubbe, 1974).

According to Gyulay (1978), staff members have observed infants as young as eight months, as well as retarded children, whose behaviour changed following the news of impending tragedy. A child who, moments before, had been crying for the attention of his parents, became quiet and sat motionless on his parent's lap as if fully understanding the impact of the news. Although death anxiety is generally associated with the older child (age ten and older), younger children are thought to be capable of experiencing death anxiety also. For example, Morrissey (1963) observed death anxiety in a 3½ year old child.

Eugenia Waechter (1971) challenges researchers who had been reporting that fatally ill children do not, as a rule, experience or express anxiety about death until after the age of 10, and are not aware of what is happening to them. She hypothesised that, despite widespread efforts in our society to shield children with fatal illness from awareness of their diagnosis and prognosis, the anxiety of meaningful adults is conveyed to them directly and indirectly. In her study, she used four matched groups from the controversial 6-10 year age range, and concluded that the denial or protectiveness of adults does not prevent terminally ill children from

experiencing anxiety, nor does keeping awareness of their diagnosis and probable prognosis from them. Furthermore, her findings made it clear that dying children can express their awareness by the use of words relating to death.

Bluebond-Langner (1977), who studied 40 terminally ill children, supports Waechter, and concludes that children pass through five different stages before they eventually realise that they are dying. After the diagnosis of terminal illness has been made, the child first learns that "it" (not everyone knows the name of the disease) is a serious illness. By the time he reaches Stage 2, the child knows which drugs are used, when, how and with what consequences. Stage 3 is marked by an understanding of the special procedures needed to administer the drugs and additional treatments which may be required as a result of the drugs' side-effects. The child knows which symptoms precede which procedure and the relationship between particular symptoms and procedures, although at this stage he sees each procedure and each treatment as an unique event. Stage 4 indicates an ability to put treatments, procedures and symptoms into the larger perspective of the cycle of relapses and remissions. The child realises that one can get sick over and over again in the same way, and that the effects of the medicines do not always help for as long as they are supposed to, if at all. However, it is not until the child passes to Stage 5 that he realises that the cycle is finite, that it has an end, and that the end is death. The child learns that there is a finite number of drugs and, when these drugs are no longer effective, death becomes imminent.

As children pass through the five stages in the acquisition of information, they also pass through five different definitions of themselves:

FIGURE 1 : Stages in the realisation of terminal illness

DIAGNOSIS	1	2	3	4	5
WELL	Seriously ill	Seriously ill, but will get better	Always ill, but will get better	Always ill, but will never get better	DYING

According to Spinetta (1978), the majority of authors are in agreement that the older child with a fatal prognosis, especially the adolescent, is aware of, and anxious about, the potential outcome of his illness.

Waechter (1971) concluded that dying children express significantly more anxiety, specifically related to fear, loneliness and death, than do other ill children, and that adults may be blinded to this anxiety because of personal fears, concerns and a sense of helplessness related to the diagnosis. Kübler-Ross (1969), Green (1967), Binger, Ablin, Feuerstein, Kushner, Zoger & Middelton (1969), Easson (1970), Feinberg (1970) and Schowalter (1970), support this idea and suggest that anxiety is caused by the isolation resulting from attempts to shield the dying child from his illness and its consequences.

"It is a grave error to think that a child over 4 or 5 years of age, who is dying of a terminal illness, does not realise its seriousness and probable fatality. Repeatedly, experience has shown us otherwise. We have seen the pathetic consequence of the loneliness of a fatally ill child who has no-one with whom he may talk over his serious concerns because his parents are frequently trying to shield him from the diagnosis" (Binger, Ablin, Feuerstein, Kushner, Zoger & Mikkelsen, 1969, p. 417).

In a study by Bluebond-Langner (1974), it was found that all the leukemic children (up to 14 years of age) observed, knew that they had a very

serious illness. Many of the older children knew that it would be fatal. All of them knew of other children who had gone to the same clinic, taken the same drugs, been subjected to the same kinds of medical tests, spent time in the hospital in reverse isolation, received blood, become bald and bloated, and then died.

Van Eys (1977) stressed the fact that not conveying the nature of the illness creates a block between parent, or caring adult, and the child. Furthermore, a child can rarely be fooled, because adults communicate the information which they would like to hide nonverbally.

When information is withheld from patients, the danger exists that a disclosure may inadvertently be made by someone in the community. Glaser and Strauss (1974) describe a teenager who learnt about his imminent death from a friend, who learnt of it from another friend whose parents, in turn, had received the information from the patient's parents. The blinding news, combined with a deep sense of his parents' betrayal, resulted (as staff members put it) in the boy's almost complete "withdrawal" and "apathy". Consequently, the staff could do almost nothing to shape the boy's trajectory as they would have wished. Even the psychiatrist who they called in could accomplish nothing.

In view of the above discussion, it is apparent that the child is aware of the fact that he will die and should be told. The role of the clinical psychologist in this respect is described in the next chapter.

It is important to remember that sharing the diagnosis and prognosis with a dying patient does not automatically imply an open and honest relationship. Krant (1974a) warns that truth-telling, by its very nature, can be

barbaric, painful and non-supportive, and can quite easily destroy an individual. Thus, the critical question is: how successfully can the parents provide an environment where the child is allowed to share his concerns, whatever they may be?

The following experience, as described by a 14 year old girl, must be avoided at all costs:

"I am 14 years old and I have leukemia. My parents and my doctor told me about it, but they never talk to me about my problems. They keep saying I should concentrate on getting well, but I'm sick a lot of the time. I can't talk to the kids at school and there is no counsellor there, since it is a small school. I'm lonely. I wish I could talk to someone who understands. I think I would feel better." (Kelly, 1979, p. 160).

In summary, then, it seems that quite often the parents' inability to confront and speak of death could lead to the avoidance of any discussion with the child about the diagnosis and prognosis.

It must be remembered that children are sensitive to the world around them, and they pick up verbal and nonverbal cues about their illness from parents, family and staff. The child will listen to footsteps, tone of voice, and visually follow visitors around the room. Children detect subtle changes: a mother's tearful expression, or the snapping together of a purse before a visitor enters the room. They are quick to feel that their parents are unwilling to discuss their illness, and as a result, they often try to protect their parents, even trying to comfort and support them.

The most lonely people the current researcher has worked with are probably dying children who suspected their terminal diagnosis, but realised that their parents did not want them to know and were not ready to talk about

it. As a result, they could not talk about their anxiety and their fears, and they had to enter death with many unanswered questions, totally isolated from the loving, caring support of their parents and family.

3.3 THE CHILD'S REACTION TO THE NEWS OF TERMINAL ILLNESS

As mentioned above, even very young children are sensitive to verbal and non-verbal messages, cues and signals from the people around them. They are quick to sense tension and anxiety in the family and staff when a diagnosis of a terminal illness has been made.

The majority of children appear to take their cues from the family as to how they should respond to their illness. In an atmosphere of open, honest communication, the child who can intellectually grasp the seriousness of the diagnosis and understands the nature of the illness as a result of exposure to television, newspapers and magazines, may feel free to ask questions and share or to keep a "stiff upper lip" because that kind of behaviour is expected and an important feature of the character of the family.

The older child may react to the diagnosis with shock and disbelief. "Are you sure?" "You must be mistaken!" and "I don't believe it", are common initial responses. Some may accept the diagnosis, whilst others may choose to deny the reality. The latter group may keep their personal thoughts and feelings vague. They may want to be closed in and also strongly resist telling and being told about themselves. Those who acknowledge the fact that they are dying, may find themselves struggling to find a reason for their illness. There may be tremendous emotional pressure to answer this usually unanswerable question: "Why me?" (Schowater, 1977).

3.4 THE TRAUMA OF HOSPITALISATION

Hospitalisation is generally disturbing for adults, despite their understanding the need for it and knowing that life and relationships will normally resume thereafter. The upset for a small child who is dependent on parents for survival and/or does not have the emotional and intellectual abilities to comprehend and cope with what is happening to him, is far greater.

Child psychiatry leaves no doubt that children are emotionally dependent upon their parents for normal development and the establishment of an independent identity. Hospitalisation may threaten the child's sense of dependence and/or independence. The child has no control over the process which finally brought him to hospital. Thus, hospitalisation is an emotionally laden and traumatic experience for children, usually charged with unpleasant implications, difficult adjustments, and separation from a familiar environment. Children usually find it difficult to adjust to hospitalisation because of prejudices, fears and fantasies which they bring with them into the hospital situation. Even the small child may interpret hospitalisation as a confirmation of the seriousness of his illness and his parents' inability to cope with the situation. Relatives, young and old, may have been admitted to hospital and not returned, and hospitals may be seen as places where people die. This view of modern hospitals is supported by television programmes about hospital life. Children may even have been threatened with hospital if they misbehave, so that they often think of a hospital as a place of punishment. The hospital may also represent a place where one loses one's personal identity, and people in white take over with institutional efficiency.

These preconceived anxieties are often reinforced by fearful sights, smells, sounds, the presence of other seriously ill patients, the change in routines and habits, and the loss of control over even the simplest everyday functions (Verwoerd, 1966). It is unanimously agreed that the best place for dying children is at home, with parents, pets, and the family environment (Martinson, 1976). However, when care needed by the dying child becomes so complex and difficult, when pain control measures increase, or when the family can no longer cope with the situation, then hospitalisation is indicated (Sauer, 1976). This is usually the time when the patient's needs are so great, or his defences so low, that he becomes uniquely vulnerable and open to emotional hurt and devastation.

Patients often feel that they are being treated as "non-persons" and dehumanised in the process of hospitalisation (Smith, 1977). The necessary medical procedures to which children are frequently subjected are often not explained. They are painful and frightening, and they are viewed with apprehension. Hospitalisation forces separation from mother and, at the same time, it introduces the child to new people, places and frequently painful procedures. Research has indicated that a child in a large, modern hospital is exposed to an average of 20 different people over a period of 24 hours (Hofmeyr, 1974). Once the child becomes terminally ill, the situation is often complicated. Adamek (1965) reports that staff in the hospital tend to avoid and isolate the terminally ill child. A study done by Le Shan, and quoted by Bowers, Jackson, Knight & Le Shan (1964), supports this notion. Le Shan found that nurses in a large New York hospital consistently hurried to the rooms of the patients who were less near death and, as consistently, dragged their feet in response to the summons of those who were at death's door. Responses to hospitalisation

vary in kind and intensity, according to the age and stage of development of the child.

3.4.1 The Pre-school Child

Up to 6 months of age, the infant is only briefly upset by the change in the environment, and separation is not experienced as being very traumatic, as long as the child's basic needs are met. Under 5 years of age, the child lacks the verbal ability to express himself sufficiently and lacks a sense of time and understanding of the reasons for procedures, which results in more intense and prolonged reactions to changes in environment, routine and procedures.

The hospital, where the majority of terminally ill children are taken, is an unfamiliar place, with strange people. The dying child is separated from his important love object (mother) and although this loss may be only temporary, the child may react in different ways. Morrissey (1963) found that 50% of children experienced considerable anxiety during hospitalisation. According to Spinetta (1978), this anxiety takes the form of separation anxiety, loneliness, and fear of abandonment.

The greatest fear is that of separation from mother, other members of the family, home and playthings. The primary fear when Mother leaves is that she will not come back because she no longer loves the child and, as a result, is glad to be rid of him. Young children are convinced that nothing happens by chance and that they are punished for bad behaviour and thoughts (Easson, 1970). Certainly, nothing can seem more punishing than abandonment and rejection by parents, in the frightening new world of the

hospital with its strange procedures. The suspicion that separation from mother is a punishment for being naughty is especially acute in a sick child (Bird, 1973; Schowalter, 1970).

Separation always makes a child anxious and unhappy. The small child responds to separation totally and absolutely. He does not understand the necessity for it and is only aware that the person in whom his expectations of comfort and security are vested is not there to meet his urgent needs, causing him to be instantly plunged into grief and despair (Robertson, 1962).

The child may not only fear that Mother has deserted him and will fail to return, but, in addition, he will inevitably experience feelings of anger towards Mother for abandoning him and making him suffer. The anger is real, but usually it is so frightening that the child cannot allow himself to realise that he feels it, keeping it hidden and expressing it in disguised form at special times. The child may express this anger by being bad-tempered towards Mother, or anyone who attempts to take Mother's place, or by thinking about and wishing dreadful things onto Mother, about which he often feels guilty and sad, and this could lead to withdrawal. In rejecting their own angry thoughts, children see staff as also being hostile to them. They believe that others can read their thoughts, as they themselves can, and therefore expect retaliation in the form of further punishment (Waechter, 1984).

Children, aged 5, are often pre-occupied with the threat to their bodily integrity and functioning, and have a pronounced fear of bodily mutilation (Schwartz & Schwartz 1972; Martinson, 1976). This fear is often exacer-

bated by the many procedures which are part of the daily routine in a modern hospital.

According to Schwartz & Schwartz (1972), who quote Bowlby (1952) and Robertson (1958), children pass through three stages in the process of "settling in" to the hospital routine. The initial stage of "protest" is a period of crying, confusion, fright, tantrums of acute dismay, and searching for Mother. This phase can last up to 10 days, and it is gradually replaced by "despair" and hopelessness, in which distress behaviour becomes less obvious and the child becomes more apathetic and withdrawn, possibly wailing monotonously. If the separation lasts long enough, the child becomes "detached", turning away from his disturbing feelings towards Mother, as he recovers an interest in his environment (Knudson & Natterson, 1960).

3.4.2 The School-aged Child

School-aged children, although they react to hospitalisation too, are generally more able to understand and co-operate. Besides separation from family and friends, hospitalisation imposes restrictions on mobility, enforces dependency, invades privacy, and threatens autonomous functioning - all critical concerns for the school-aged child who is in the process of emancipation from his parents.

Feelings of helplessness, embarrassment and irritation are often experienced. To be "treated like a child" is often more upsetting to the school-aged child than to an adult. A bedridden child, unable to dress and feed himself and to use the bathroom without help, resents the loss of such

recent gains in his development. The less ill he feels, the stronger his resentment will be. The various attendant bodily manipulations are often perceived not only as attacks upon drives for independence, but also as threats to functional and sexual integrity. Anger, humiliation, and anxiety about the backward pull toward a state of helpless dependency are frequently observed, and the hospital staff and the parents may become the targets of defiant protests. However, some children regress to more babyish behaviour without much protest, and need considerable help to regain achievements in motor and social functioning after an illness.

Injections, infusions, immobilisation, surgery, and other procedures arouse anxiety beyond the discomfort involved, because they reactivate the universal childhood fears of bodily mutilation and disfigurement and the illogical views of medical procedures as a punishment for actual or imagined misdeeds. Such fantasies generally cause fewer problems in the older school-aged child, because his strides in cognitive development enable him to comprehend the causal and temporal relationship of an illness or injury to a greater extent.

Most sick children find immobilisation and restriction of activity emotionally stressful. They rely on freedom of movement to discharge tension, to express dissatisfaction and aggression, and to explore and master the environment. Sudden or prolonged motor restraint of a child can cause him to panic, develop temper tantrums, and become a serious management problem. At other times, he might show the opposite reaction of withdrawal into an apathetic, depressed state. The child with poor ability or lack of opportunity to verbalise his feelings is more prone to show marked behavioural reactions to forced restraints (Hofman, Becker & Gabriel, 1976; Mattson, 1977).

3.5 THE DYING CHILD COPING WITH SYMPTOMS, PAIN AND TREATMENT

3.5.1 Symptoms

A child's response to symptoms experienced is age related.

3.5.1.1 The Pre-school Child

According to Easson (1970), the newborn infant reacts to the physical stress of dying with innate physiological reflexes, striving to maintain life as long as possible, barely aware of the outside world and relating to people and things through touch, smell and sound. Words do not yet have meaning to the newborn infant. Unmet physical needs may lead to experiences of pain, hunger, and breathlessness, and are expressed by crying out in natural anxiety. If the tension is not relieved, the cry becomes distressed, then panicky and, finally, it may subside into a beaten apathetic whimper.

The infant struggles for relief from death agony, but is not really able to be comforted by human contact. Maximum physical relief and comfort can make dying easier, but in a certain sense the infant dies in a solitary fashion. Parents need support as they struggle with their emotions whilst helplessly watching their newborn.

It is important to remember that children, as they mature, are only able to face their own dying with the primitive understanding and limited emotional strength of the very young. Young children are dependent upon their parents for their existence, and rely on them for direction about what they should do and just how they should feel. As with their reaction to the diagnosis of terminal illness, children take their cue from their parents

and significant others (staff) as to how they should respond to the disease process. Their personal dying only has meaning to them as it affects the people around them.

Burton (1975) emphasises the fact that infants and pre-school children are essentially egotistical and that they rarely compare themselves with others. As a result, they normally accept their symptoms, however gross. Infants and young children seem to adapt best to alterations in life style necessitated by disease. On the other hand, the older the child is at the onset of his symptoms and the greater the freedom he has previously experienced, the more difficult it is to accept the limitations of the disease.

When parents are obsessed with, and distressed about, the symptoms to such an extent that they refrain from touching their child or handling the affected areas, it has a profound influence on the child and may result in acute anxiety, withdrawal and depression. According to Burton (1975), children respond more to their parents' feelings than to the actual disease manifestations.

3.5.1.2 The School-aged Child

Generally it is not until children emerge from the age of egocentricity and start comparing themselves with healthy brothers and sisters or intact schoolmates, that they develop genuine discomfort concerning symptoms. Their reactions will depend upon the exact nature of the symptoms and the degree to which they interfere with the gradual unfolding of their abilities. The reaction of other people to their illness and symptoms will

influence children's own responses. When symptoms are obvious disfiguring, children may respond with shame and embarrassment, especially if they are met with aversion and fear by others. This is especially true of children whose illness has a late onset and who have not, therefore, spent their pre-school years accommodating to their disability. The child with cystic fibrosis, for instance, has to cope with such embarrassing symptoms as flatulence and stool odour, with the complex management of postural drainage and nebulisation, and with growing awareness that the illness is hereditary, progressive, and carries a poor prognosis (Mattson, 1977).

When physiological and other upheavals, such as intractable pain, severe mutilation, or profound interference with organ function, interfere with calm and control so that personal dignity is lost, the patient may become dehumanised in his own eyes (Verwoerd, 1966).

Mental and physical distress are often closely interwoven. At this age we see the outset of confusion in the terminally ill, and also the frequent combination of anxiety with breathlessness, of depression with nausea and feelings of guilt, with incontinence or an offensive discharge. Schowalter (1973) stresses the fact that children, relatively more frequently than adults, reflect their psychic discomfort as bodily discomfort. They may express these feelings through complaining about physical symptoms, which they know will be acceptable.

3.5.2 Children and the Experience of Pain

Pain is a symptom which many people commonly fear will be the dreadful accompaniment of their terminal illness. Furthermore, it is not easy to assess with any great accuracy the intensity of pain felt by dying patients

(Hinton, 1968). Children's perception of pain often differs from that of adults, and it is frequently more difficult to determine the sources of pain (Buschman, Sheets & Wharton, 1973). All children show evidence of pain.

3.5.2.1 The Pre-school Child

Infants may find it difficult to distinguish the area from which the pain emanates, and may respond to it in a gross way. The hospitalised toddler feels the pain of separation from parents as acutely as the pain associated with the disease process. As the child grows older, the pain becomes more specific and the child's ability to detect and report it improves. However, frequent questions arise about the child's subjective response to discomfort, about whether a child's behaviour is an expression of subjective reactions to pain or the anticipation of pain (Schowalter, 1973).

3.5.2.2 The School-aged Child

As the child grows older, emotional distress plays a large role in the pain experience of most patients. As stated before, it is a well documented fact that for various reasons, parents and staff often tend to avoid and isolate dying children. The dying school-aged child may demand more attention through increased frequency and intensity of physical complaints. Although such complaints are frequently a conscious attempt at manipulation, more often they reflect a genuine increase in the intensity of physical discomfort (Schowalter, 1973). Therefore, one may suggest that anxious children are usually also children whose physical distress is

enhanced, and it is not unusual for a circular pattern to evolve in which anxiety leads to more pain, which increases anxiety. Relief of anxiety results in relief of pain. Parents are often unsure of how much their child is suffering and can be greatly perturbed about the possibility that their child could be in pain. They may feel helpless and unable to alleviate the pain. As a result, they may become militant and demanding (Hinton, 1968). Furthermore, children may blame their parents for causing and allowing pain. This can be very disturbing to parents, because they often feel responsible for what is happening to the child and their guilt is exacerbated by their helplessness.

3.5.3 Children and treatment

Generally, children adapt best when the treatment required is commenced in infancy and becomes part of life's routine. With older children, those diagnosed beyond infancy, treatment may be disliked because it becomes a symbol of the illness, accentuating the difference from others. The more obvious the therapy, the more equipment involved, the less the child can disguise it and the more embarrassing it will become (Burton, 1975).

Some treatment procedures undoubtedly have a punitive aspect, for example, those requiring bedrest or immobilisation, swallowing unpleasant substances, or a limitation of food intake. Understandably, some children faced with such treatments see them as evidence of rejection, or view them as punishment for wrongdoing, possibly a retaliation for becoming sick. Such children need reassurance about their fears, especially concerning any sense of guilt or responsibility they may have. In extreme cases, perceptual and bodily disturbances and acute loss of identity may be found in children whose treatment demands physical isolation.

It is often thought that children kept on treatment over lengthy periods of time eventually adapt completely to it, and that they accept it. This is rarely the case, especially when treatment procedures are unpleasant, cause discomfort, or interrupt normal life (Burton, 1975).

3.6 THE CHILD IN REMISSION

The remissions and exacerbations during the course of chemo- and radio-therapy in the treatment of malignant diseases in children result in repeated episodes of alternating hope and despair in parents and the children themselves. Remission is a relatively new phenomenon, resulting from breakthrough in medical technology and medical science.

When parents and child are told that remission has been attained, the child expresses immediate relief. Even young children seem to sense the good news by the reaction of others. Upon discharge from hospital, the child and his parents must begin a new life - although life will never be the same as it was before.

Once a remission is induced, the child's major concern shifts from fear of death to an acute sense of being different; different from his former self and different from his peers. He may, in fact, be visibly and conspicuously different from his former self because of amputation or alopecia. Even apart from such drastic changes, a boy may be sensitive to weight loss which has shrunk a formerly athletic physique, so important to self-esteem in the high school world. It also seems to the adolescent that everyone in the world knows about his illness and is either sorry for him or does not know what to do about him.

The child may have ambivalent feelings about leaving the hospital, where safety and protection were provided in a time of crisis. The situation at home may be totally different. There may be an uneasy silence, meant to suggest normalcy although both the parents and the child know that, in spite of the remission, the prognosis is still the same. Often the parents and child fear that mentioning the disease will bring it back. They seem to hope that the reverse is true - that by suppressing their thoughts about the disease, it, too, can be suppressed.

Throughout the remission, children must return to hospital for many kinds of therapy, medication and physical examinations. Young children often care only about the procedures and are relieved when they are over. Older children, however, dread both the procedures and the results which they may bring. These results are extremely important, determining whether the child remains in remission and on the road to a possible cure, or whether the day of relapse is drawing near. Children intently watch all people involved. Every smile, frown, quizzical look or facial expression can inspire terror or relief. Any change in procedure, with or without explanation, causes alarm. Clinic visits become exhausting experiences for both parents and child, and they are physically and emotionally drained after each visit.

During remission, parents may go to extremes to protect their child from a return of the disease symptoms. Every ache, pain, symptom or remark is scrutinised. As a result, in some cases children conceal or deny complaints, fearing that they will have to be readmitted to hospital, or that a painful procedure will be performed.

Often parents find it extremely difficult to discipline their child during

remission. Children challenge their parents and limitations placed on them, and remissions are often characterised by family conflict and tension to the point where children may express their desire to return to hospital.

The anxiety and dread which have been suppressed during remission return when a child is readmitted to hospital. With exacerbation of the illness, the good days are often quickly forgotten and parents and child think only of the dismal future ahead. Often they feel frustrated, angry and depressed. "It's not worth all we have gone through." (Gyulay, 1978; Wessel, 1984; Plumb & Holland, 1974).

Bergman & Freud (1974) have noted that for each readmission, fears and anxieties belonging to former occasions are revived.

"The readmission to the hospital brings with it the painful memories of the first admission, as well as a host of new anxieties and disruptions in the family's life. Regardless of the number of relapses, the transition from life at home to life in the hospital is never orderly

Both parents and child may have forgotten what procedures, regimes, and routines were involved in hospitalization. After readmission, they all seem to take longer and to be more painful. Remission seems as remote as if it never took place." (Gyulay, 1978, p. 98).

3.7 THE EMOTIONAL WORLD OF THE DYING CHILD

3.7.1 The Pre-school Child

As the infant grows older, he develops an increasing awareness of himself as a discrete individual and a separate human being, with a sense of autonomy and a will of his own. He learns through testing his own strength

and perceptions that he has an unique physical body, and finds out, by expressing his opinions and emotions, that he has a personality which is distinct and different from other people and other things around him. During this period from 2-4 years of age, the growing child comes to understand the meaning of "myself" and "I" (Easson, 1970).

Waechter (1984) is of the opinion that threat to body image may cause distress to young children at a time when they are beginning to form a concept of self. Whereas healthy children are now becoming comfortable with the functioning of their bodies, the bodies of ill children are under constant assault. Even very young children may be quite concerned about physical changes (an increase or loss of weight, the loss of hair) as a result of treatment. Because of the egocentricity and lack of empathy in children of this age, the child's playmates and other children may respond critically and negatively to his appearance.

As the child begins to grasp the very significant fact that he has a separate and unique identity, he must start to face the inescapable reality that this identity may come to an end. Thus the growing child develops the concept of non-existence. Normally and naturally, those disturbing feelings are covered over and blocked away by denial and repression. Sometimes the stress placed on him by such new knowledge will nevertheless show through an increase in nightmares or other behavioural changes, such as greater play aggressiveness or concern about the death of others.

The child who weakens physically as the disease advances, finds himself emotionally weaker and thus less able to deny the increasing threat to his being. The restlessness of the dying child may be an outward indication

that he is becoming less and less able to contain and control his anxieties as death grows nearer and he senses within himself that his end is near. Dying brings with it an enforced dependency, and the child may resent bitterly the fact that he can no longer do what he wants to do, in the way he likes to do it (Easson, 1970). Physical limitations and distress may lead to the child internalising fears, and as a result he may whine, become highly dependent, or fiercely independent. The child's behaviour may fluctuate with the degree and severity of the illness. At points of severe distress, the child may vary from marked withdrawal and full panic to endless demands on his parents (Barbero, 1971). Regression to more infantile behaviour, such as bedwetting, thumbsucking, rocking, temper tantrums and fluffy toy clinging (Renshaw, 1974) allows the dying child to become very dependent on his parents.

Easson (1970) states that because the pre-school child has no clear concept of time, he may feel the separation of death to be merely an overnight sleep, with the assurance of parental love on the awakening. With this support and understanding, the pre-school child can die, secure in the firm belief that his parents will not leave him. With certainty that his parents accept him, good as he is and naughty as he may sometimes be, the young child can pass through these final stages of life; tolerate the discomfort of death, and die in peace.

3.7.2 The School-aged Child

During the school years, the growing child moves out of the protection and security of his house into the world, to become a meaningful member of society in his own right. The child starts to go to school and begins to spend more time with peers, friends and classmates. School and organised

group activities become more important. However, although he becomes more independent, he is still closely involved with the family. When he has listened to, and learned from, the opinions and attitudes of teachers, schoolmates, television performers and newspaper headlines, he always comes back to his family for a firmer, final opinion, depending on his home for security and continued stability. It is only with this assurance and continued family support and protection that the school-aged child can experiment and test, experience new pleasure and pain, grow and develop, and take risks (Easson, 1970; Easson, 1977; Gyulay, 1978).

Waechter (1984) emphasises the fact that the school-aged child has many more resources available to cope with threat, and that he is able to communicate thoughts and feelings verbally to a much greater degree than the pre-school child. Many 7-8 year old children are familiar with the disease process, and some arrive at their own diagnosis, even before it is finalised, saying: "I have read about leukemia and I have the symptoms." In a certain sense they are "experts" on their diseases.

The school-aged child is able to grasp the implications of his diagnosis. He realises the impact which his illness will have on his life, his independence and his place in the world (Gyulay, 1977). As indicated before, a number of children experience the same shock and denial over their diagnosis as their parents do. Frequently the older child goes from shock to anger, and denial to embittered acceptance: "You're right, this life is not for me!" he says belligerently. Emotional reactions to the diagnosis are often so mixed that it is difficult to distinguish anger from denial, or guilt from depression. Realising that their illness may be life-threatening, children of this age display feelings of guilt, fear, anger, and anxiety. They may still perceive their illness as punishment,

no longer by parents, or staff, but by God - or some other supernatural power. At this stage of development, children can realistically understand the relationship between the disease and its effect on the body, as well as the specific purposes of the various medical procedures (Wass, 1982; Wass 1984).

Terminally ill children will experience anxiety at some level of consciousness. Its effects depend upon the child's emotional reserves, coping mechanisms and the degree of support received from his immediate environment (Tropauer, Franz & Dilgard, 1977). They perceive that something serious is wrong with them through a nonverbal transfer of anxiety from all people who deal with them (Toch, 1977). They respond to many of the cues, although they do not necessarily tell other people how much they know.

Toch (1977) stresses the fact that children accept adult statements as factual and literal, and that only extreme exaggerations will be recognised as such. However, communication with school-aged children is often difficult. Not only are their powers of verbal expression still limited, but their thoughts often do not follow rational adult patterns. Their desire for information is intense, but rather specific, so that when they want to know something, their interest is usually limited to the specific item.

Fear, particularly of the unknown, is an inherent component of human emotions. The school-aged child will probably have outgrown the unreasonable fears of earlier childhood, but these fears may be revived when he is struck down with an inexplicable illness (Toch, 1977). These fears may relate closely to the nature of the illness and may be accentuated by deaths of other children.

Conspicuous during this time is a sense of growing entrapment: "I can't be committed to anything. I can't do anything This is the first time I feel the leukemia". Anger is often felt although it is at times too terrifying to express directly. The child is angry with himself, with parents, staff, and with other patients. He may direct his hostility towards the team and may resist co-operation in the treatment régime or he may openly reject his parents, making such statements as: "I hate you and I don't ever want to see you again", with the result that the parents feel that they have, in some way, failed their child. This pattern of behaviour may appear after the child has been ill for some time, and is angry with his parents for being unable to prevent painful procedures and prolonged hospitalisation. Furthermore, children sense their dependence on the medical and nursing staff and may be fearful of expressing hostility directly towards these individuals (Friedman, Chadoff, Mason & Hamburg, 1963).

During this stage, when concern with their bodies becomes more pronounced, severe anxiety is experienced about possible disfigurement and other adverse changes in their bodies, resulting in feelings of inadequacy (Tropauer, Franz & Dilgard, 1977). Where illness manifestations are very obvious, the child may respond with shame. Pain may evoke feelings of anger and resentment or, alternatively, masochistic submission tinged with guilt and depression. Waechter (1984) stresses the fact that the child's involvement with peers and school often compounds the child's concern about appearance. Loss of hair, jaundice, stunted growth, obesity, or amputations, are sources of great distress for the child. Very often the image of self changes into "bad", "rotten", "a piece of garbage", and as a consequence the child may see himself as worthless and become dispirited (Burton, 1975). Children can be helped to feel that they are acceptable

and loved in spite of bodily disfigurement, and they can learn to cope with their illness and the side-effects of treatment. In this way, interference with somatic functions can be considered a challenge, as Toch (1977) suggested, rather than a handicap.

All these feelings may be accentuated because the child is often unable to distinguish between feelings of suffering caused by the disease inside the body, and suffering imposed on him from outside for the sake of curing the disease (Green, 1967). Waechter (1984) feels that school-aged children, although becoming increasingly independent from their parents, still need them when they become ill, lonely, frightened and sad during hospitalisation. However it is important to keep in mind that some children may use their illness to become manipulative with peers, teachers and parents, as well as with siblings and, as a result, they may become difficult to discipline.

3.7.3 The Adolescent

Erikson (1963) stressed the fact that the adolescent is faced with a physiological revolution within himself during which time he has to cope with vast bodily changes, as well as redirect intensified sexual impulses towards appropriate objects outside the family. In addition, he begins to face the intellectual, social and vocational demands of adulthood, which lie directly ahead of him. Furthermore, he is concerned with how he appears in the eyes of others, and compares this with his feelings about himself. He is also confronted with the question of how to connect the roles and skills cultivated earlier with the demands of tomorrow.

Thus adolescence is that period of psychological growth when emancipation and individualism occur. Intimately connected are both the development of adult sexuality and true abstract thinking. Hofmann, Becker and Gabriel (1976) relate the major issues of these years to the acquisition of autonomous function and the determination of one's own role apart and separate from that of family members. To accomplish this, the adolescent must discover ways of putting distance between himself and those upon whom he has relied for nurturance, protection and love, with the ultimate goal of taking over from them without precipitating their rejection and abandonment. The task is an enormous and frightening one, even under the best of circumstances.

According to Easson (1970), most teenagers free themselves from their family in a gradual process during which the family ties are loosened; at the same time there is a gradual development of emotional bonds to the peer group. As a result of this "rejection" of the family, the adolescent may feel vaguely and uneasily guilty.

As we have seen in the previous chapter, the adolescent's concept of death approximates to that of an adult, and death is seen as real, total and final. For the adolescent, becoming aware of the fact that he is going to die triggers one of man's deepest fears - death before fulfilment (Schowalter, 1970). The adolescent's death means not only that there is nothing in his future, but that the time spent in growing up was wasted. In addition to guilt and depression, the adolescent is also bitter, angry and bewildered.

When he learns about his diagnosis, virtually every adolescent undergoes an alteration in his concept of himself as an individual. The knowledge that

he has a disease which will require long-term treatment and could end in death immediately means to him that he is "different". At an age when "belonging" is so important, the feeling that he is not like others because of the defect which his illness represents to him, produces a feeling of inferiority and loss of self-esteem. His immediate concern is not "Will I die?" but "How will this disease make me different? How will my friends react to the different me? Will I be rejected?"

Immediately after the diagnosis, and especially while he is among peers, he denies his illness and insists that he is normal. The necessity to deny the illness underlies his unwillingness to inform others of his disease. This denial may be so strong that he continues to participate in activities which he pursued prior to the diagnosis, even if these are deemed harmful (Moore, Holton & Marten, 1969).

Once the adolescent patient acknowledges that he is dying, the most common thought expressed is "Why me?" and there is a tremendous need to find an answer to this question. Some adolescents try to cope by intellectualising, asking questions about their disease and avidly reading articles about it. Intellectualisation helps them to master the anxiety produced by the illness - it enables them to isolate the feeling from the thought, repress the feeling, and place emphasis on the rational aspect of the knowledge. However, it is usually inconceivable to the adolescent that such an unspeakable horror as cancer is not the fault of something or someone. They often blame themselves, finding reason for their illnesses in sexual fantasies or experiences, arguments with parents or peers and poor physical hygiene. Religious adolescents may curse God for causing the illness, for not protecting them, or for being impotent in restoring health. Other adolescents complain bitterly about the unfairness of it

all. Schowalter (1977) quotes an adolescent as saying:

"I can take everything except the damnable fact that there is no earthly reason why this should be happening to me instead of you or anybody else."

The adolescent may know that he has done wrong and broken many rules, but he is deeply shocked at the magnitude of the punishment which also implies rejection. Because he is resentful towards those people on whom he still depends, and for whom he cares deeply, his quiet depression and helplessness deepen. Many dying teenagers feel that no-one can understand them and they face death lonely and alone.

This is further exacerbated by the separation from their peer group. Very often, according to Easson (1970), teenagers withdraw emotionally when faced with the impending death of one of their own age group. Death, and especially the death of a friend and someone their own age, emphasises their own vulnerability and fragility and these newly independent teenagers cannot tolerate this kind of open manifestation of their very human frailty. They tend to pull back from anyone who faces them too openly with these feelings, and they cannot cope with observing disfigurement or mutilation - thus isolating their dying friend.

Waechter (1984) concludes that dying adolescents are also partly responsible for their isolation from peers. In defending themselves against the threat of abandonment by friends, they often deny their need for them by emphasising their own self-sufficiency and independence. Terminally ill adolescents may also be envious of their peers who are developing identities as young adults, developing physically, relating happily to the opposite sex, and breaking the emotional bondage to their parents. In

contrast, the dying adolescent is about to lose everything - his dreams, hopes, aspirations, independence and mobility. Instead of being able to take pride in his physical development, he finds himself trapped in a weak, inadequate, disfigured body, which he despises. Adolescents fear the loss of control resulting from taking drugs, more so than do younger children. They fear passivity and dependency (Wass, 1982; Wass, 1984).

Death can only mean defeat to the adolescent, on the brink of exploring and mastering the world. In waiting for death to come, some may be fearful, inactive and isolated, with marked dependency on their families. Others may become overly independent, resentful and bitter, often engaging in dangerous risk-taking behaviour, defying treatment and procedures. Still others who have become disfigured may find adjustment totally engulfing and frequently crushing. They lack self-confidence, have a low self esteem, worry about their handicaps and their lack of skills, and show signs of real misery and depression. Their altered physical appearance may mean loss of attractiveness and femininity to girls, and loss of sex appeal and virility to boys. A much more drastic alteration of body image occurs in patients who, because of bone tumours, require amputation of all or part of a limb. In an age group where physical integrity is highly valued, the loss of a limb has tremendous emotional significance. They are lonely people, harbouring resentful and hostile feelings towards all normal people whom they see as owing them payment for their suffering and eventual dying (Mattson, 1977).

During these years, adolescents are sensitive about their normal strivings toward independence and, particularly, resent enforced dependency and loss of freedom, so typical in modern hospitals (Czaczkes & Kaplan De Nour 1978). Plumb & Holland (1974) pointed out that teenagers as a group are

more concerned with symptoms than they are with the overall process of life-threatening illness. Symptoms, less obvious but ever present, may be resented because they are found to have a limiting effect on activities. Dying adolescents may soon realise that the changes in their bodies will prove not to be a vital asset to their fulfilment, but a fatal liability. They may worry that their symptoms will prevent them from getting a job, or establishing a relationship with someone else (Burton, 1975). They may experience not only a general decrease in vitality, but also suffer the consequences of X-Ray or Chemotherapy (increased fatigue, nausea, vomiting, easy bruising, etc.). These physical ravages of terminal illness are least easily endured by the adolescent, as at no other time in life are physical beauty and prowess such critical standards of one's popularity or success (Schowalter, 1970).

Singularly sensitive to physical discomfort, adolescents experience pain with heightened intensity. While stoicism may prevail in the face of physical injury on the athletic field, or be masked with bravado amongst one's peers, in the hospital setting the converse is true and here adolescents often respond with considerable regression and decompensation. Many teenagers recall their pain as the most distressing memory of these events, together with the apparent insensitivity and unresponsiveness of the staff to this fact (Hofman, Becker & Gabriel, 1976). Older children may become increasingly negativistic if their pain is allowed to persist. They may respond to their illness with rage and resentment, especially when mismanaged, and this may prejudice their immediate physical well-being and long term adaptation.

In coping with the intense threat of premature death, adolescents make great use of denial, which often permits them to live with their illness.

As time passes, the adolescent draws emotionally closer to members of his family. He can allow himself to accept the caring of warm and loving relationships. In a trusting, respectful atmosphere, the patient and the family can do their grieving. Waechter (1984) points out that the adolescent usually selects one or two adults with whom to share his thoughts and feelings in the terminal phase. Some younger adolescents may resist to the end, lonely and proud, but this is relatively rare. In many cases, as death nears, adolescents show amazing strength, comforting their parents who are in pain and providing meaning to this tragedy by teaching others the values and ideals of living.

3.8 THE CHILD AND FINAL DEATH

Children's reactions during the final phase differ from person to person. Dying is always a very individual experience.

When the process of dying is prolonged, abandonment becomes a problem. Parents, family members, and even staff members, may isolate the patient both physically and emotionally. Isolation may lead to loneliness and fear. The fears experienced during the final stages are essentially the same as those experienced all along: fear of pain, death, physical deterioration, loss of control, etc. Often parents may want the child sedated, even when this is not medically advisable, for fear of the child experiencing pain.

Pattison (1977, p. 55) describes the final phase as a period when the patient begins to withdraw:

"Perhaps it is like the experience we may have with a bad case of flu. We feel terribly sick, lose interest in food, activities and friends. All we want to do is curl up in a warm bed and be left alone in quietness."

As the human body approaches death and physiological homeostasis becomes increasingly disrupted, the body fights for survival. Children experience physical disequilibrium and may try to share this awareness by saying to their parents that they feel "strange", or that they cannot breathe.

Hours, or even minutes, before death the child may become very alert. He may express his love and appreciation for his parents, asking forgiveness for things done wrong and for all the trouble caused. He may want to be reassured that his parents will not abandon him. Sometimes the older child may wish death would come. Children may show considerable strength in supporting parents in their sadness.

CHAPTER 4

CARING FOR THE DYING CHILD

4.1 INTRODUCTION

There are few things more difficult for hospital staff than working with a child who is dying. A child with cancer or other chronic and debilitating disease, has often struggled through periods of remission and relapse and endured intensive medical treatment. Many of the behaviours of the dying child and his family are repetitions of responses which have been learned during the course of the illness. Care-givers are thus faced not only with the challenge of providing excellent physical care, but also with the need to understand the child and those who love him (Adams, 1984).

4.1.1 The Multi-disciplinary Team

During recent years, with increasing specialisation in modern medicine, it has become evident that no one person can provide for the diversity of needs of the dying child and his family. Much has been said and written about the medical team operating in modern hospitals (Martinson, P., 1976; Lamerton, 1973; Childress & Harrison, 1971).

In the hospital situation, the dying child becomes the responsibility of the multi-disciplinary team. Easson (1970) regards every person who comes into contact with the dying person, and who is concerned about his welfare, as a member of the team. Traditionally, the team consists of:

- (a) The physician, who is seen as the source of medical knowledge, able to diagnose, prescribe and give information about the illness. Historically, the physician's role has emerged as being that of the leader of the team, and he and the head nurse usually take responsibility for the team's operating as a unit, co-ordinating the

physical, psychological, social and spiritual care of the child.

- (b) The nurse, who assists the patient to obtain or maintain those requirements basic to health, and who directs or manages him so that unnecessary, painful or dangerous situations or circumstances are avoided or modified, thereby encouraging the highest level of independent functioning. The nurse is often seen as the manager of physical comfort and a constant companion.
- (c) The social worker, whose knowledge of family dynamics and of community and social resources makes her a resourceful person to the rest of the team. Social work skills aim at maximising the social functioning of the individual, with a special focus on interpersonal relationships and social roles which, in turn, profoundly influence the manner in which people meet and deal with various crises in the life cycle. She interviews, assesses, and follows up those patients and family members who have particular problems in these areas.
- (d) The physiotherapist critically assesses the patient's physical capabilities and will help him to understand his limitations, enabling him to function with the greatest possible independence in the face of diminishing resources. She advises team members regarding positioning and transferring the patient and therapeutic devices available for patient comfort and self-functioning. If an occupational therapist is not available, the physiotherapist may be familiar with occupational therapy techniques and may use these when working with patients and their families.

- (e) The dietician, experienced in the nutritional care of patients, seeks to provide frequent, small, attractive servings of food which the patient will enjoy.
- (f) The chaplain provides resources for the patient and family which technology cannot provide. At the sociological level, the chaplain enhances the pre-existing strengths of the family so as to guarantee continued relationships of wholeness. At the symbolic level, the patient and family are encouraged to build upon their prior moral and religious resources, so as to continue to move towards the reconciliation of self with society and final reality (Ajemian & Mount, 1980).

Furthermore, the catering staff, the steward who brings the daily paper, the domestic and office staff, the volunteer worker, are all people who come into contact with the dying patient and can make a positive contribution to his life. They are thus all regarded as members of the team.

Each member of the team should not only have a clear definition of his role and an understanding of the world of the dying child, but should also be aware of the contribution which the other team members can make in caring for the dying child and his family. For this reason, conscientious efforts are made to encourage communication between members of the various professions, to serve the welfare of the dying patient. At times, specific roles and responsibilities of team members may overlap, and team members may find themselves involved in activities which may be foreign to their familiar role. For example, a nurse may comply with a child's request to say a prayer, or the chaplain may wipe the brow of a vomiting child.

4.1.2 The Clinical Psychologist as a Member of the Team

It is noteworthy that, in spite of Freud's interest in death and Eissler's attempt (1955) to delineate the special role of the psychiatrist in counselling the dying patient, the psychiatrist and clinical psychologist are conspicuous by their absence whenever the team is mentioned or described (Wiener, 1970). Even Kübler-Ross (1969), herself a psychiatrist whose timely publication "On Death and Dying" initiated new interest in this area, only mentions the doctor, nurse, social worker and chaplain as the major people in providing the necessary care. A reason for this attitude may be that death has traditionally been the realm of other professionals such as physicians, clergymen and funeral directors (McKittrick, 1981). However, Weisman (1979) contends that psychiatrists generally are uninterested in death and, therefore, not only lack experience but know less, care less, and have no established and acceptable role in providing for the needs of dying patients.

However, most large hospitals have psychiatric services, and in general hospitals there is already the encouraging example of liaison psychiatry, which is primarily concerned with how physical illness impinges on the human condition or, conversely, how a patient's psychosocial plight puts pressure on physical well-being. Liaison psychiatrists and clinical psychologists are increasingly becoming participating members in the management of problem patients on the basis of formulation as well as insight (Hackett, 1977). It is possible and desirable that this participation will extend to involvement in the care of dying patients and that psychiatrists and clinical psychologists will come to be regarded as valuable members of the interdisciplinary team.

The present author believes that the clinical psychologist has a special role to play in the team. When the child becomes terminally ill and death becomes a reality, this is exactly the moment that the clinical psychologist can move beyond the other members of the team who have done their best to restore life, but have lost the battle. This is because a competent, conscientious clinical psychologist may discover or reveal psychosocial dimensions in the terminally ill child which other members of the team have perhaps failed to recognise. The main purpose of psychosocial intervention is to help vulnerable patients to accommodate better, mitigate more effectively, and come to terms with their prevailing plight with less distress. The clinical psychologist can join forces with the dying patient, helping him to grow to fulfilment, finish unfinished business, to grieve and to loosen himself from this world and his loved ones, eventually to die a dignified death. At best, this task is a complicated and difficult one, but when the patient is a child it becomes even more demanding and challenging.

In today's achievement orientated society, where performance and productivity are basic requirements for acceptance and progress, the clinical psychologist, together with the chaplain and social worker, is in a sense different from the other members of the team. Other team members invest in the patient and expect performance in return. Medication is administered, nursing care is provided, surgery is performed, radiotherapy is administered, and the patient is expected to respond positively in return. The clinical psychologist, the chaplain, and the social worker, do not perform any role in the sick room. They do not perform or "treat" the patient. They come to be with the patient and this frees the patient to be with them, each one in a different way.

The world of the dying child has been described in detail in the previous chapter. This chapter will examine the task and responsibility of the clinical psychologist as a member of the team. The psychologist, in particular, has theoretical knowledge of children's ways of thinking and their emotional reactions, and has experience in relating to children. The clinical psychologist is thus exceptionally well trained for this task, but professional training can never be separated from the person who happens to have had the training. In the final section of this chapter, attention will be given to the psychologist himself and various methods of coping.

4.2 INFORMING THE CHILD ABOUT HIS DISEASE

The controversy surrounding the question of whether a child should be informed about his illness and prognosis was discussed in Chapter 3. It was concluded that it is essential to share honest, clear and accurate information and, in this way, build up a trusting relationship with the child. Trust is the cornerstone of open and honest communication.

Children who choose to communicate openly and honestly about their illness are able to do so because of parental attitudes supporting them, and a family history reinforcing openness (Spinetta, 1978). Results of a study by Slavin, O'Malley, Koocher & Foster (1982) support the hypothesis that early knowledge of the diagnosis is related to good psychosocial adjustment among long term survivors of childhood malignancies. The majority of survivors, parents and siblings who were interviewed, advised telling the child his diagnosis at an early stage. Many of the parents who did not initially share the diagnosis with their child, identified this lack of candour as a source of stress or other difficulty, both during and after the treatment period.

Many parents who had told their child about the diagnosis at an early stage, reported that they simply never hid the truth from their children and could not break that family rule even in the crisis of terminal illness. Openness could be seen simply as one manifestation of good family mental health, which is also attributable to other factors, and tends to endure naturally throughout the illness experience. By using an open approach with parents, professional caregivers can provide models of adaptive behaviour for them. Such modelling could help families with a dying child in active treatment to learn healthy, open styles of communication and coping together.

White (1977) stresses the fact that in discussing the diagnosis with patients, it is important to make sure that the family is involved in such a discussion. If a patient knows one thing and the family another, communication is diminished by at least that amount. He acknowledges the fact that a small minority of people would not be able to tolerate such a discussion, but stresses the fact that they are the people who will quickly forget that such a discussion ever took place.

Several authors (Waechter, 1971; Vernick & Karon, 1965; Binger, Ablin, Feuerstein, Kushner, Zoger & Mikkelsen, 1969) have pointed out that telling the child per se is not really the most important issue. More important is the need to provide a climate of openness and support for the child in dealing with his serious illness.

It was pointed out in the previous chapter that from a very young age children sense, through their parents' attitudes and behaviour, that something serious is wrong with them, despite the parents' efforts to

protect their children from the reality of their diagnosis and prognosis. The non-verbal messages he receives, the increase in gifts, the frequent surprises and favours, and the sudden curtailment of discipline, make the terminally ill child more insecure than he would have been had his parents told him truthfully that things were destined to be unpleasant because of his illness. Vernick (1973) found that children who knew about their illness, were concerned about other terminally ill children in the ward, and were more honest with certain staff members than with parents. Nothing is more tragic than to watch worried parents anxiously denying the severity of their child's condition in order to protect the child, and the child manfully struggling to maintain the pretence in order to protect his parents (Burton, 1971). Such a child may choose silence because he is aware, even at a level preceding his ability to express this, that the family does not allow communication about the illness (Spinetta, 1978).

In discussing the illness, diagnosis, treatment, and prognosis, it is extremely important to keep in mind the child's intellectual and emotional maturity, which is closely related to his understanding of the concept of death and dying, discussed at length in Chapter 2. No child may be burdened with information which cannot be conceptualised and integrated. Neither should a child be told anything which may induce psychopathology. Here the psychologist's only guide is his clinical experience and intuition, and the response of the child to the psychologist's comments and manner while accompanying him in the course of his illness (Boyd, 1977).

All children should be given the opportunity to ask questions of the clinical psychologist, who must visit the child, preferably when the parents are not present. He may be asked to answer questions on a wide range of topics, ranging from heaven to white cells. Children ask

different questions and have different concerns and needs at different stages of their illness. When they are first diagnosed, they may be concerned about the serious nature of the illness and about the fact that they are sicker than they have ever been before. They may be most anxious about how their illness or therapy will interfere with their normal pursuits or affect their appearance and most of their queries will address these points, denying the real implications of their disease. Until the child is better known and a good relationship has been established, the psychologist must be careful not to press matters too far, giving the child only the information which he is ready to hear. When the child begins to achieve remission, he may want to know about the drugs used in his treatment and their side-effects. He is interested in his apparent recovery from the illness. However, when he experiences his first relapse, old doubts will return. He wonders if he will always be sick, and tries to learn everything about the procedures which he will have to endure. When he suffers further relapses, he may ask questions about the chronic nature of his illness, and may want to know if and when the suffering will ever end (Bluebond-Langner, 1977).

In coping with all these questions, there is no fixed protocol and no set guidelines may be laid down when we enter the area of open communication and truth. Every child is unique and must be approached with the utmost consideration, empathy, love, willingness to listen, and a willingness to allow him to talk about what he knows, and to ask questions which are important to him. If this is done, there may be no need to ask whether the child should be told about his impending death or not. The child will do the telling.

Questions are a form of reaching out for support and understanding. If the

child is comfortable enough to ask about his illness, his questions should be answered openly and honestly. He should be told only what he asks. The dying child will indicate by his questions what kind of answers he wishes to hear. However, while answers to the patient's questions should always be honest, the psychologist should also be sure of what the child is really asking about. If the intent is uncertain or confused, it can be clarified by asking: "Can you tell me a little more about what you have on your mind?"

It must be remembered that honesty does not mean brutal frankness: "You're going to die and that's it!" Rather, it implies supportiveness which will protect the dignity of the child. If he asks, "Am I going to die?", and some do so directly, it is important to find out what he is thinking and to respond to his question simply and with at least some hope (Adams, 1984). The answers could be: "We all will die some day, but you are not going to die today." This response supports the child's need to deny, if necessary, but equally tells him truthfully what could happen tomorrow (Van Eys, 1977; Easson, 1970). If the child emotionally needs to deny absolutely, he should be allowed to maintain this emotional defence, particularly when he is plagued by blatant and continuing symptoms of his illness (Plumb & Holland, 1974).

The child should not be obliged to face unpleasant and unbearable realities which he cannot tolerate. Different children require different degrees of honesty, some being able to cope better with reality than others (Burton, 1971). Truth can be shared in small increments, and the child can be allowed to digest, absorb and grow in truth. At times, ambivalence may be noted. On the one hand there may be the acceptance of death and willingness to give up life and yet, at other times, there may be antici-

pation of a future (Krant, 1974 b).

The psychologist should seek to discover and correct any misinformation which the child may have acquired, by providing frequent opportunities for him to ask questions and to describe his own understanding of his illness and treatment, whilst simultaneously being allowed to express his feelings about it. Older children often like to have a name for the illness - something they can call it when talking to others. If the disease is inevitably fatal in a very short time and the child has little energy available to wrestle with and correct, if necessary, the connotations he attaches to the name, then it is doubtful if the real name should be used unless the parents, on careful reflection of all the issues, wish to be totally open about the disease and all its implications. If the name is used, the older child will almost inevitably find out all about the illness from books or other people, if he is still capable of doing so. Adolescents may also read indiscriminately about the disease. The psychologist must ask about sources of knowledge, and discourage such reading because of the despair and panic which could result from reading an outdated article, or the false optimism which might arise from a premature "cure" report. Children should be encouraged to ask for information in order to correct their fantasies about their illness through the provision of factual information. This will maintain the child's trust (Moore, Holton & Marten, 1969; Howarth, 1974).

A child, testing another's willingness to talk with him about his dying, may raise questions about the seriousness of his illness. If the person questioned shows a high level of anxiety by denying the seriousness of his illness or by projecting false hopes, or by avoiding issues, the dying child will have found out what he sought to know, namely, that no one is

willing to share with him in his struggle to come to terms with the reality of his imminent death. The child may then choose to play the game and join the conspiracy of silence. It may happen that every time a dying child feels an intense need to talk about his death, he is denied the opportunity to do so. This leaves him in emotional isolation and alienates him from those whose anxiety about dying leads them to avoid the subject. Thus, despite the fact that he needs and yearns for warm, human contact, he feels completely alone. Simply affirming calmly the full critical nature of his illness, and facing with him, honestly but gently, the uncertainty of his recovery, frees the dying child to expose his own anxieties and to deal candidly with whatever issues are important to him. Sometimes these issues are as practical and mundane as wanting to see his dog once more, or giving a present to a friend, and in this way setting in order the affairs of his every day life. Sometimes they become philosophical to the extent of theorising about the total meaning of the universe, and especially about the possibility of life beyond death. There is no predicting what turn such conversations will take as time goes by, but what is important to the dying child is the opportunity for full participation in a community of persons who love him, who care about him, and who are willing to talk to him about his dying. Only such loving experiences can support his life with strength and imbue it with meaning.

In summary, the author fully agrees with Lasagna (1972, p. 34) who says:

"I have come to believe more and more that honesty is one of the few things in this world that is important."

Lies always prove to be fatal. When a child discovers that he has been lied to, he may feel betrayed, unsafe and lonely. If his questions are answered evasively or untruthfully, the dying child will sense that he is not being responded to directly. He may feel, with justification, that such a lack of directness is a sign of disrespect, which places him in an

inferior and dependent position. When he is dealt with on the basis of respect, the dying child can respond with much more self-control and co-operation. It is important to be honest and share clear and accurate information and, in this way, build up a trusting relationship with him. Trust is the cornerstone of open, honest communication.

The author is committed to the view that dying children should be advised of their diagnoses in terms which they can well understand. However, this should also be firmly coupled with all realistic prospects for cure or remission. If reasonable hope is a part of this discussion, one can assume that the young patient will, at least early in the course, quickly latch onto the most favourable aspects. He will experience less anxiety, be more co-operative and, in general, cope with his situation more effectively once these matters have been brought into the open.

4.3 THE PSYCHOLOGIST AND THE HOSPITALISED CHILD

The trauma of hospitalisation for a child of any age has been discussed at length in the previous chapter. Schoenberg & Senescu (1970) state that more than half of the deaths in the United States of America occur in hospitals. Although childhood deaths have become relatively infrequent due to social changes embodying improvements in domestic hygiene, nutrition, and living standards, they still occur, be it after an accident, poisoning, from congenital abnormalities or malignancy (Dodge, 1974). The majority of these children eventually die in a hospital. The statistics for South Africa are not available, but the trend set in the United States will probably be followed here. Because of lengthy treatment procedures, the increase in life expectancy of children with a malignant disease, and the

succession of remissions and relapses, children will, even if they eventually die at home, find themselves in hospital for shorter or longer periods. At times, hospitalisation may be significantly prolonged. For this reason, adequate preparation for hospitalisation is of the utmost importance. Once in the hospital, the child needs help in dealing with pain, symptoms and treatment procedures. The psychologist can play a major role in helping the child to cope with these experiences.

4.3.1 Preparation for Hospitalisation

As mentioned in the previous chapter, children may have many fears, some realistic and some based on misconceptions or fantasies about hospitalisation. Among these are fears of pain, disfigurement, disability and even death. For this reason, it is important that children be prepared for their hospitalisation and procedures such as surgery or radiotherapy, through clear, simple and repeated explanations of what is to be done, and why. These explanations should be suited to the child's level of intellectual and emotional development. Children should never be tricked or deceived into being admitted to hospital, but should be told ahead of time that they will be going there, the reason why, and what they may expect to happen once they are there. Older children may be told a long time in advance. Children from 4 to 6 years of age could be told four to seven days ahead of the time, and children aged 2 to 3 years could be told a day or two before admission. The child needs time to assimilate this information, to ask questions, and to act it out in play activities. The child may need time to discuss the proceedings numerous times with adults and with other children, in order to correct or clarify misunderstandings and to integrate his knowledge emotionally as well as intellectually (Paterson, 1978; Danilowicz & Gabriel, 1976).

The clinical psychologist, working in a modern hospital, should meet the parents and the child on their first visit to the Oncology Clinic, as a routine occurrence. With the increase in the number of private hospitals, the paediatrician at such hospitals should refer the parents and the child to a clinical psychologist, upon suspecting the presence of a terminal disease in the child or, at the latest, immediately after the diagnosis of a potentially fatal disease has been confirmed. The advantage will be that when the decision is made to hospitalise the child, the clinical psychologist can use the already existing relationship to prepare the child and the parents adequately for this. The psychologist may use parents as allies, advising them on answers to possible questions, and on ways in which to stimulate play activities which will help the child to integrate the knowledge of the experience awaiting him. With sufficient time available, the child may be invited to the psychologist's playroom, whether it be at the hospital or at his private practice. A visit to the hospital and to the ward can also be arranged, where the various items of apparatus to be used will be seen, examined and even observed in action.

It is essential to prepare the child for all medical procedures. The child should not be given unrealistic reassurances. It is a mistake to tell the child, "It won't hurt", if the procedure is painful, or to say to the child, "I'm going to give you a tiny mosquito bite", when in fact preparing to do a spinal tap. It is important to be honest and to tell the child that the procedures may be painful; that no-one wants to hurt him but that helping does sometimes hurt. By taking time to provide the child with the required information, we demonstrate that he is regarded as a worthy person and this creates a feeling of trust and safety.

It is important for the child to be certain that the people involved in his

treatment have his best interests at heart. In addition, these explanations can be coupled with some hope of alleviation and improvement in the future, so that he may anticipate the future without despair (Wass, 1982; Burton, 1974b). If the psychologist suspects that a child has a particular concern about his illness or treatment which he is unable to verbalise, it is sometimes useful for the psychologist to tell the child a story about the feelings of a boy or girl who had to undergo similar procedures and what happened to that child in the hospital. This may help the sick child to acknowledge that he had been feeling like the child referred to, and may enable him to ask further questions about his own specific situation. An example of this technique in the case of the mother of a five year old boy, suffering from a brain tumour, used to tell her child a story about a little prince who fell sick and developed a nasty pain in his head. She would say, "Whilst he was getting better, his mother stayed with him all the time and talked to him, and kept him from feeling lonely. When his head hurt, the doctor would come and help to make it better. The doctor and the prince's mother were always near the prince, keeping him safe and comfortable, and making sure he was never alone."

Older children require careful explanations regarding the nature and usefulness of the required treatment régime (Burton, 1975). Awareness of the cause of pain and an understanding of the purposes of treatment, spare the child the experience of meaninglessness, helplessness and hopelessness described by Le Shan (1974). Great care must be exercised to maintain verbal and emotional contact with such children, and they must be reassured that treatment is only being administered for their own good and that it will be discontinued as soon as possible. Children not only need adequate preparation before surgery, but afterwards they also need the opportunity to work through their feelings about the experience. Some

children may act out the procedure quite spontaneously in play with another child or with dolls, perhaps assuming the role of a doctor or nurse rather than that of a patient. This may help the child to achieve a sense of mastery over a situation in which he was relatively helpless. Other children may appear quite passive and even withdrawn, and may need the help of the clinical psychologist to explain or act out their feelings about their experience. Still others may react to procedures by becoming uncharacteristically aggressive and belligerent, and they may need the full attention of the psychologist and perhaps even have limits set to this behaviour. In any event, the psychologist can play a major role in helping children "debrief" their experience, by encouraging them to talk out their feelings concerning the procedure, or to act them out in play, in non-destructive ways (Paterson, 1978).

4.3.2 The Hospital Environment

Rigid, time-honoured hospital rules should not exist for the dying child and his family. The child must be provided with love, honesty, security and contentment, and with as normal a life as possible. He should be dressed in his own clothes, and personal toys and love objects must accompany him to hospital. This will usually help in overcoming the strangeness of the environment. Terminal illness frequently means revision of long term goals for the child, and planning on an almost day-to-day or week-by-week basis. Normal activities are strongly encouraged. Mother should be encouraged to continue daily routines in the case of a toddler or pre-school child. Children should be up and about whenever possible. They must be helped to do things themselves, no matter how long these might take or how difficult they may be to manage. They should be treated the same as well children whenever possible, and encouraged to participate in hospital

school, occupational and recreational activities. They can also be used to run errands in the ward, and should be praised for the smallest accomplishment, of whatever nature. It is important to reinforce the dying child's self-worth by continuing to set up goals which enhance life and, where feasible, result in even minor accomplishments (Adams, 1984).

The care of the dying child includes all that can help him to live as normally as possible until he dies. The help given to him in hospital must be suited to him and to his own background. It must be planned for him personally, and his own individuality and dignity should be kept in the forefront of all planning for him (Krause, 1976; Saunders, 1973).

The child should also participate in his disease process as far as possible. Participation in decision-making may take many forms, from the question of where an IV should be started, or where he would like to have his injection, to whether specific treatment should be continued at all. Some adolescents do indeed refuse treatment and should be allowed to do so. Permitting a child to assist in some small way with the procedure will minimise the feeling of helplessness and foster a sense of control (Van Eys, 1977; Wass, 1982).

The question of whether or not to segregate dying children on the hospital ward usually arises. This should be handled with sensitivity by considering the child's condition and exploring the wishes of the parents and the other patients in the room. Isolation, whether as a result of passive withdrawal by the child or active avoidance on the part of the staff, must be absolutely avoided. The clinical psychologist can play a major role in such circumstances by helping the staff to deal with their "unacceptable", angry feelings toward the child for not responding to the treatment and

possibly also towards the parents who may be anxious and hovering. He can also provide support and security for the child who possibly experiences the total disintegration of his familiar environment.

Whenever feasible, the child should not be placed in a private room since contact with other children makes the adjustment to hospitalisation more tolerable. Dying children seem to have a particularly intense need to keep in contact with other children, and through them with the outside world. Adams (1984) mentions that he encountered several terminally ill children, ranging in age from 2 to 10 years, who demanded that their parents pull them around the ward in a wagon. For older children, the value of the telephone, flexibility in visiting rules, and allowances for short absences from the ward with family or friends, must be considered. Adolescents value their mobility and their friends, and although new associations help, an opportunity to share time with his peer group may be the best tonic for a depressed adolescent patient.

The toddler or pre-school child, who is discovering independence and mastery, may view hospitalisation, with its painful procedures, as punishment. The child at this stage needs a great deal of reassurance that hospitalisation is neither punishment nor rejection. It is a good idea to explain the cause-effect relationship between hospitalisation and disease, disease and its effects, and disease and medical procedures, even if the child does not completely comprehend. The psychologist should do so at every opportunity and in different ways, and should encourage parents to do the same. By actions and words, the child's parents must emphasise to him that they are not angry with him and that they love him very much. They can understand that he resents hospitalisation and that his anger is realistic (Easson, 1970). Furthermore, the psychologist should encourage

the parents to become active supporters and participants, and not passive gift-givers. In this way they not only stay involved and gain insight into the child's world, but also provide the child with a much needed feeling of safety and confidence that he will not be abandoned. The child needs his family to feel safe and to protect him. He needs the security of Mother's presence, sitting at his bedside. He gains much strength from Father's hand quietly holding him. The family can "mother" him and help him cope with the stresses of hospitalisation.

Easson (1970) points out that when the young child is dying, he really needs his mother if he is to cope with the experience. Even a small child, as previously suggested, is sensitive and reacts to the emotions of those around him. The clinical psychologist can effectively help parents deal with their emotional struggle as a result of the approaching death of their child. This will be discussed at length in the following chapter. Mother and Father can gradually introduce members of the treatment team to the child, so that he gradually becomes more comfortable and secure with them, and begins to use them as mother and/or father substitutes. In this way, the psychologist or any other member of the team may become a member of the child's family - able to comfort, help and treat.

The drive for independence which is curtailed by his illness and the treatment procedures, coupled with the anger which the child feels towards himself for causing all this, may be suppressed within himself or directed at his parents, possibly even at the nursing staff, or at other children in the ward. Methods of dealing therapeutically with the anger and channeling it in as productive a fashion as possible, will be discussed later in this chapter. At this stage, it is necessary to mention that it is important to permit the child to express his anger as a natural thing which

is neither good nor bad, just as it is acceptable and natural to express pain (Easson, 1970; Krause, 1976; Wass, 1982).

4.3.3 Helping the Child to Deal With the Concomitance of Pain, Symptoms and Treatment Procedure

The severity of pain experienced by the dying child may be difficult to estimate since minor pain may be exaggerated or severe pain minimised, but the intensity of pain in childhood is often indicated by the emotional reactions of the child. It is most important to have the patient under observation at all times, in order to assess the extent of pain adequately. It is part of the competence of the physician to attend conscientiously to the patient's complaints and attempt to minimise physical pain and discomfort by whatever means necessary.

Before the clinical psychologist can help the child with the emotional stresses which may attend a child's dying, it is necessary to control physical pain. Persistent, severe, physical pain leaves a child and, for that matter, anyone an easy victim of anxiety, depression and anger. An evaluation of the relevant factors involved is essential. The establishment of strong rapport in the relationship between the psychologist and the child, and, the attempted relief of underlying anxiety, depression, loneliness and hypochondriases, are basic to the management of pain (Verwoerd, 1966). The presence of a caring person, who listens and attempts to understand the sensation of pain which the child is experiencing, is perhaps one of the most important factors in its relief (Lack & Buckingham, 1978). This contention is supported by Kübler-Ross (1969) and Lamerton (1973), who concur that the presence of someone who spends time visiting

and listening is a fundamental need of the dying child, and is essential in the control of pain. The psychologist's opinion could be most valuable to the physician who has to make decisions and prescribe the necessary drugs.

There is no reason why any child, and especially a dying child, should be in physical pain, and no effective analgesics should be withheld. Adolescents often single out delays in medication, or inadequate dosages, as the greatest deficiency in their care. Effective and prompt analgesics must be given as needed, throughout the course, without the spurious, denying rationalisation that the patient will become addicted (Evans & Edin, 1968; Bakan, 1968; Koenig, 1973; Mennie, 1974).

Each person develops and incorporates into his self-concept a mental representation of his body and its parts - its shape, the real and symbolic functions of parts or organs, and what constitutes the integrity of the total self. This representation is referred to as "body image". Varying from person to person, parts of the body and body image are endowed with certain real and symbolic meanings, important to individual psychosocial adaptation. Damage to the body and the body image is thus not only a physical event, but has psychological consequences as well (Barton, 1977).

Having to surrender to others control over bodily functions which the child attained proudly, may be experienced as the most painful backward step. The 3 to 4 year old is mortified when placed in diapers again. After all his efforts to become independent and free from wet pants, to be put into a position of dependency and treated like an infant, could be most traumatic. However children may differ in their reactions to this change. One may submit without apparent difficulty while another may fight against his

helplessness and suffer from the shame of physical weakness such as incontinence. In such cases, the child's body image and ego can be damaged by remarks, looks of disgust or impatience with the incontinence.

The psychologist should take time to explain to the family and hospital staff the psychological impact of physical regression, and can thereby encourage the staff and parents to be gentle, loving and reassuring to the child. Constant praise of other intact faculties in such children is vital. Even grossly deformed children can accommodate to their handicap if handled with sufficient sensitivity and if parents assist children by providing the "correct" clothing, school equipment or hair-do (Burton, 1975). Both parents and children should be warned in advance about the possible appearance of symptoms, and it should be stressed that they are not responsible for this, through any negligence on their part. Considerable fear and anxiety can be prevented when symptoms are thus understood and anticipated.

Our modern society emphasises youth and vitality, and places tremendous importance on physical appearance, resulting in less tolerance of the disfiguring effects of disease. This sometimes leads to total rejection of such patients. As a result, a great source of anxiety is the patient's fear that friends and staff may reject or abandon him. Under these circumstances, the work of the clinical psychologist with a disfigured child is difficult and complicated. Basic to the caring is love, which means that the child is perceived as precious, priceless and of immeasurable value, and this will determine the manner in which the psychologist should relate to the patient. With the younger child, words are less important than physical presence - the touch, or the holding, which gives a child a feeling of being accepted and loved in spite of gross deformity and bad

odours. The basic principles of Psychosynthesis, as described by Assagioli (1965), could be followed by the psychologist in his psychotherapy with the older, more verbal, child. The exercise in "dis-identification" (pp. 116-125) can be used most effectively. In this exercise, the child is helped to become aware of and to affirm with conviction the fact that he has a body, but that he is not his body. He is led to understand that the body is something material and changeable and that he mistakenly identifies himself with his body and attributes to his "I" his physical sensations. His body may find itself in different conditions of health or sickness; it may be rested or tired, but that has nothing to do with his self, his real "I". His body is a precious instrument of experience and of action in the outer world, but it is only an instrument. He treats it well and seeks to keep it in good health, but it is not himself. He has a body, but he is not his body. In this way, he can be helped to dis-identify with his body which is riddled with cancer, and still regard himself as precious, receiving and giving love. The author has found in his work with dying adolescents that once these principles are intellectually grasped and emotionally integrated, both patient and therapist experience a new-found freedom.

Associated with the loss of bodily function is the curtailment of motor activity. This may lead to intense feelings of anxiety, anger and aggression. In his normal life, the child has had adequate opportunity for the necessary discharge of energy and he may have coped with his anxiety by biting his nails, and with his aggression by playing rugby. Deprived of mobility, he has limited options. The psychologist could help to provide outlets for his frustrations through verbal experience and - as long as practicable - through suitable play material and artistic media, like finger-painting or drawings. The psychologist can use innovative and

creative means to find an appropriate and suitable therapeutic medium to meet the specific needs of each child (Gordon, 1974; Koenig, 1973).

Caring is intertwined with respect for human dignity and all this entails. Conscientious efforts should be made to help a dying child feel that he is a person of worth in a modern hospital, where treatment and staff can easily become clinical and cold. Personal care involves attention to detail and an awareness of, and respect for, individual differences and responses. In many instances the dying child is physically quite helpless, and daily care involves compassionate patience and understanding, combined with meticulous physical care.

Taking time to explain procedures, to honour preferences, to respect privacy and modesty, to consult with the patient concerning his feelings and needs, to involve him in social and recreational activities, and in small celebrations, reflects recognition of his personal worth and conveys to him the certainty that he still matters; that he has not been "written off as finished". Caring also means the availability of the person who is so easily hidden beneath the mask of professional language, impersonality, ritualised action and hospital routine. Availability is the key to helpful interactions with the dying child. It means listening and talking. It means closeness, but not smothering or infantilising. It means that the child is accepted, even when angry, sad or complaining.

Caring means keeping the child physically and emotionally comfortable, maintaining conditions as near to normal as possible, and allowing the child to do anything and everything he is capable of doing for himself, until death ensues (Cotter, 1971; Schowalter, 1977; Van Eys, 1977).

4.3.4 Alternative Places of Dying : Hospital or Home

The question of whether a child should stay in hospital until death or perhaps go home has received much attention recently. A brief discussion of this controversy is included in this section.

Something of the complexity and diversity of the needs of a dying child has been outlined so far. It follows logically that considerable knowledge and understanding is required to provide for these needs and to help a child to die peacefully and with dignity. The availability of a team with members who are professionals in their different fields of specialisation is essential to provide the total care needed by the dying child and such care is superior to the care offered in an individualistic, isolated manner by any one individual. The modern hospital, where the medical team operates, would then, in theory, be the ideal place for any patient, whether young or old, to spend his last days and finally die. However, it has been pointed out that admission to the modern hospital with its highly complicated, highly specialised machinery, its restless atmosphere and sharply timed procedures and techniques, is a highly emotional experience, if not a traumatic one. The modern hospital is often a difficult place for the dying patient and his family. The professional staff face heavy demands when dealing with treatable patients and, as a result, untreatable patients and patients with poor life expectancy, are frequently given low priority. Death is looked upon as a failure, and the dying patient is, in a sense, an embarrassment. A dying patient will sometimes apologise for being such a trouble, possibly feeling guilty for taking time from those with a good chance of recovery, who absorb much of the staff's attention (Krant & Sheldon, 1971). Therefore, children in the final stages of cancer who are admitted to hospitals, are admitted to die. The hospital, with all its

technology and highly skilled personnel, may not be essential in caring for the dying child and, in fact, it may well be an obstacle to the provision of appropriate care.

In recent years it has been recognised that although the hospital offers much, the home environment may offer more, both to the dying child and his family (Martinson, 1976). If the family has reached consensus about caring for their child at home, is able to cope emotionally, physically and materially, and has access to a supportive network of helping relationships which provide a back-up system of resources and people, it will be most likely to cope better with the bereavement and there will be less pathology as a result of unfinished grief (Binger, Ablin, Feuerstein, Kushner, Zoger & Mikkelsen, 1969). Kulenkamp (1976), herself a parent of a child who died, points out that care at home is less disruptive to the child, provides the comfort of familiar surroundings, enables interaction with the whole family including pets, allows access to the child's friends, makes parents feel their inadequacies to be less visible, and enables even brief escapes to pleasant places more readily than does the hospital (Adams, 1984).

The home care programme, as devised by Dr Ida Martinson (1976), would appear to be the ideal solution to this problem. In this programme, the team, still based at and operating from the modern hospital, provides the necessary services to a family which is caring for their own child in their own home. They provide the personal service and assistance required for physical comfort and emotional support. At this stage, research on home care programmes has been minimal and is still foreign to South African society.

4.4. THERAPEUTIC INTERVENTION WITH THE DYING CHILD

In caring for the dying child, the whole area of emotional expression assumes immense importance because, in his confrontation with his own non-existence, the child is often overwhelmed by a wide variety of intense emotions, as described in the previous chapter. Dying children may often feel unable to cope with the intensity of these feelings.

It is extremely important for the psychologist to recognise, label and understand the child's varying emotions. Furthermore, he should be able to decide on therapeutic interventions which enable the child to accept these feelings as his own and to deal with them in such a way that their crippling effects on him will be lessened. In this way, a feeling of well-being, even in the presence of death, may be achieved. This section explores different ways of dealing therapeutically with these feelings.

4.4.1 The First Interview with the Dying Child

The psychologist's management of the dying patient and his family begins at the first encounter, when death seems a remote possibility. By this time, the physician would have spoken to the parents, and sometimes the child, about the possibility of a life-threatening illness, or he may even have confirmed his diagnosis. Since the psychologist is usually not present during these moments, he may lack first-hand information about what the doctor has conveyed, how it was done, and how the family and patient reacted.

The first few interviews with the child are of crucial importance. They are door-opening interviews, in which two people meet in such a way that

they are able to communicate without fears and anxieties. The psychologist must see the child as an uniquely developing and whole person - with complex emotions and social and intellectual needs - who will respond to his dying in a very individual, unpredictable way. During these interviews, the psychologist must elicit from the child his knowledge and understanding of his illness; its meaning and implications for him. The format of a standardised psychiatric interview can be followed, which will help the psychologist to place the patient within a familial, psychiatric and social context. A standardised mental state examination will help the psychologist to observe evidence of stress and coping manoeuvres. Anger, grief, guilt, depression, etc., which the patient could not communicate to the family (Weisman, 1972), may be detected during such an examination.

The respect which the psychologist has for the child as a human being countermands the authority and power which adults normally possess and which can easily overwhelm the dying child. The psychologist will demonstrate this respect when he truly attempts to understand what the child is communicating, whether verbally or through body language and behaviour (Wass, 1982; White, 1977).

The psychologist must let the child know, by his own words and actions, that he is not going to retreat, either physically or emotionally, if the words "cancer" or "dying" are mentioned. The child may pick up this cue and open up, or he may let the psychologist know that he appreciates the message, although the time is not right. The child will let the psychologist know when he is ready to share his concerns, and the psychologist will reassure him of his return at an appropriate time. The benefits of having the same psychologist work with the child throughout should not be under-

estimated, as this leads to continuing trust on the part of parents and other family members, including the dying child (Adams, 1984).

The psychologist must go out of his way to learn to know the child well, and to establish personal rapport with him. This task is facilitated by a simple mental exercise suggested by Wass (1982), in which the psychologist must suppose for one minute that he is in the child's place, and imagine how it feels and what he needs. Rapport developed during the initial period can be of inestimable value in supporting the child through the difficult later days (Toch, 1972). This relationship between psychologist and child goes beyond the usual sympathetic and kindly manner which most people adopt in relation to sick children, and it implies that the psychologist not only respects the child as a person, but also attempts to gain knowledge of his temperamental characteristics and his reactions to previous crisis experiences. This will enable the psychologist to predict the child's reactions to the new events facing him.

The day-to-day practical implications of this approach are that the psychologist can take an interest in things of importance to the child: pets, hobbies, school activities, friends, past successes and hopes for the future. It means remembering the child's birthday and other important events. But, even more important, the psychologist will constantly try to see events and experiences from the child's point of view, and be alert to the child's ways of expressing feelings of unhappiness, discomfort, anxiety, etc. The psychologist must let the child know that he understands how he feels, and give him a chance to talk about it if he wishes to (Howarth, 1974).

Howarth (1974, p. 132) suggests an introduction which could possibly be

used by a psychologist visiting a dying child:

"I am one of the psychologists here, working with Dr I see many of the children who come to the hospital with all sorts of illnesses, and they tell me what it feels like being ill and being in hospital. Some children when they are ill are sad, or worried or upset, and some are not. We know a lot about how to make people better and how to keep them comfortable, and we would also like to make sure that children do not get too sad or upset by coming to hospital and having treatment.

We need to know what children think about being ill and having to come to hospital; what they like and don't like, what upsets them and what doesn't.

Can I ask you what you think about it all?"

He also suggests areas of enquiry which could possibly stimulate the child and elicit attitudes, ideas and feelings about the things which may be important to him. The following questions could be asked:

"How long have you been coming here?
 Why do you have to come here?
 When did it all start?
 How did it start?
 How can you tell you have an illness?
 Has the doctor told you anything about it? or the nurse - or your mother or father? or, did you get any idea what was wrong with you when the doctor spoke to your mother or father?
 What did they say?

What do you think caused your illness?
 What happens inside you to make these (symptoms)?
 What sort of things do you have to have done here? (blood tests, medicine, etc).
 What other things do people have to have done to make them better sometimes?
 Have you been ill before?
 When? What sort of illness?
 Have other people in your family been ill much?
 Mother? Father? Brothers? Sisters?
 What about friends, or children you know at school?
 Who is your best friend?
 Who else do you play with?
 What do you like doing together when you are not at school?

- and from here a general enquiry about his emotional life and relationships can be made in the usual way."

Children who are ill are not always easy to work with, for they can get as

angry, bad-tempered and rebellious as any groups of well children, but because they are unwell and terminally ill there is sometimes a tendency for adults to feel uncomfortable when such a child is reprimanded. Love, care, empathy and permission to express pain and anger should not, however, be interpreted as a *laissez-faire* attitude with respect to the child's behaviour. Hospital staff should clearly delineate rules and regulations concerning the child's behaviour, just as parents in their guilt should not dispense with normal behavioural boundaries. Unpleasant behaviour should not go unchecked. Children, whether they are sick or well, need the security of limits imposed upon them. They respond positively to behavioural guidance which is carried out in a constructive manner (Wass, 1982; Oswin, 1974; Schowalter, 1977; Adams, 1984).

4.4.2 Individual Psychotherapy

The age, emotional maturity and intellectual ability of the dying child are determining factors in deciding to engage in individual psychotherapy. A common basic assumption of psychotherapy is that the therapist works with a patient to increase the value of his long-term productivity, his relationship with others and, perhaps, to improve his adjustment to his environment. Clearly, these are not valid goals for the dying child. Rather, it is important who the patient is and what he does during the remaining life span - that is, what it encompasses rather than how long it is in chronological time. The starting point of psychotherapy generally is the attempt to help the patient shape his life in the future. In the case of a dying child, the horizon is limited to the NOW; to the patient's life and respect for it, whatever the time limit. The terminally ill child, with a limited life span, has needs which can potentially be fulfilled by psychotherapy. Unfortunately, very little therapy has been done, or is being done, with

these patients. It is vitally important for successful therapy that the therapist wants the very best for his patient, that he has dreams and visions for him. Only if this is true can the patient learn to accept and value himself, to really want the best for himself even though he may be without a future (Le Shan & Le Shan, 1961). Thus, the immediate goal of psychotherapy is of a reparative or adaptive nature, rather than a reconstructive one. For the therapist, the usual problems are multiplied and exaggerated, for he already knows that this child will die, and feelings of helplessness, failure and grief on the therapist's part are inevitable. The problems faced by the psychologist, as therapist, and possible ways of dealing with these, will be discussed in a later section.

The goal of therapy with the dying child will therefore be to enhance the child's ability to live deeply, in spite of distressing circumstances. Emphasis should be placed on renewing emotional participation in life. In uncovering underlying thoughts and feelings the therapist should guard against causing more pain and distress than he alleviates.

The patient can gain tremendous value from working with someone who believes in him enough to really wish to help him towards greater self understanding and inner growth, at a time when he cannot "repay" by a long period of adequate functioning; by growing up to become "a big, strong and successful man". His being is cared for unconditionally, and so he learns to care for it himself. The presence of the psychologist affirms the importance of the here and now. Under such circumstances, life no longer seems to have the primary quality of something which is fading away, but takes on new meaning and validity.

In his search for identity, the older child can overcome his psychic

handicaps and find a meaning in life which he had never found before. The psychologist can help the child move towards his own inner nature, towards realising his positive resources and achieving his own potential as a person. If the psychologist focuses on the child's strengths and positive qualities and those factors which block their full expression, rather than on pathology, the child may increasingly come to value and to accept himself, his universe, and his fate. In this way, the child will retain self-esteem and respect for the self until death. He will maintain his identity through contact with those who have been, and are still, part of his life, and these relationships will fulfil their mutual and individual needs (Schoenberg, 1970; Le Shan & Le Shan, 1961; Bowers, Jackson, Knight & Le Shan, 1964).

Insight into their own behaviour can be valuable for older children, and the psychologist can be very helpful in enabling the dying child to understand his own feelings. Along with this insight, and as part of the exploration of thoughts and feelings, can come an understanding of parental and staff behaviour, complete with a sense of relief and liberation. Sometimes, after insight is gained, dialogue between the child and parents can be facilitated. This dialogue can help parents understand and accept their child's needs, especially his need to express feelings. This encounter can also lead to recognition of the inevitable need of the adolescent to rely more and more on his parents as death approaches (Adams, 1984).

The primary need of the dying child then is alleviation of his loneliness and isolation, by sharing his feelings with another person who can offer support, comfort and new insights. The psychologist's primary goal is to assist the dying child by enabling him to live at his highest level of

functioning in all spheres of behaviour, so that he may maintain gratifying relationships, continue activities, and approach death with a positive self image.

It is important to keep in mind the characteristics which distinguish therapy with the dying child from therapy with the non-dying. Shneidman (1978) differentiates four major categories: content, level, meanings and role. In therapy with the dying child, there should be a more consistent focus on the affective (emotional) content. The reality of impending death replaces ordinary reality. Hard facts are under-emphasised, while feelings are stressed.

Both latent and manifest level messages are discussed with the dying child, but emphasis is placed on the manifest level by the psychologist who focuses more on acceptance and empathy, even if this means promoting dependence and regression. Latent meanings of many manifest topics (burial arrangements and disposition of personal matters) may involve wishes for continued control and immortality, and need not be made explicit.

Whereas talk about unconscious meanings constitutes a major part of the professional therapeutic situation with the non-dying, conscious meaning perceived from, and communicated to, the dying patient assumes greater importance because, simply due to a lack of time, hidden and deeply repressed unconscious meanings cannot be "worked through". Unconscious latent implications are not ignored, but are only pointed out if the interpretation may yield immediate relief.

With respect to roles, the thanatologic process presents the psychologist with unique transference and counter-transference situations. The presence

of agreed-upon equality - between the patient and the psychologist - is a paramount feature of working with the dying, quite different from the ordinary professional exchange relationship. Added to the role of therapist is also that of survivor, preserver of continuity, messenger and spokesman of unfulfilled desires.

Negative transference related to being let down, or to envy and resentment of the "injustice" of it all, is encouraged in free expression. Positive transference need not be analysed and interpreted. Instead, it should be encouraged and accepted. In fact, it is therapeutic if the dying child develops rather strong feelings of essentially positive transference towards the psychologist as this decreases feelings of isolation. Feigenberg & Shneidman (1979) are of the opinion that it is desirable to create a situation of intense transference from the very beginning, a technique which in ordinary psychotherapy might appear to be unseemly or contraindicated. They feel that there is something ineffably special and sometimes rather dramatic in the transference which occurs with a dying person.

Where strong transference feelings are manifested in therapy with the dying child, there may also be considerable counter-transference. The psychologist may genuinely like the child and feel concerned about his welfare. As a result, there is also the unavoidable psychological price: vulnerability and grief over the eventual loss. There cannot ever be any investment without running the risk of loss. Thus, counter-transference should be carefully monitored, recognising that an extraordinary investment in the patient is permitted in the special situation of the patient who, from the first session onwards, is dying. Dealing with a dying child is abrasive psychological work, and the psychologist is well advised to have

good support systems in his own life - loved persons, friends, congenial work and peer consultants (Eissler, 1955; Hacker, 1977). Psychotherapy, once initiated, must usually be continued as long as the patient requires it, despite the physical limitation of confinement to home or hospital. As stated before, a primary requirement is the psychologist's availability, which the patient should be allowed to test and verify for himself.

4.4.3 The Use of Projective Methods of Expression

Emotional expression by a dying child may be facilitated by the introduction of a number of verbal or non-verbal methods of eliciting emotionally-laden material. This section outlines some of the techniques which may be used by the clinical psychologist, as part of his intervention with the child.

4.4.3.1 Artistic Media (Expressive)

The process of artistic creation in different media has been a means of self-expression for millenia. By deepening his awareness of the creative process, a person may resolve and clarify this expression of himself. This resolution and clarification releases energy and permits the person, whether child or adult, to develop and grow further. For younger children, however, indirect means of expression can be of tremendous value.

In a relaxed atmosphere, whether in the child's own room or in a therapy room, the child can express his deepest conflicts and problems. Art acts as a catalyst. A child can paint, draw, act out, or model in clay, scribble, splash and colour. The end result is not as important as the

doing and the child is encouraged to talk about and explain his creations. This will not only help the child to get his feelings and emotions out into the open, but will also enable the psychologist to identify sources of concern and consolation (Bertman, 1979; Stevens, 1971).

In spontaneous drawings, with free choice of form, colour and design, the dying child very often reveals his knowledge of his own impending death, and is able to share with the psychologist the symbolic language, the meaning of his illness, his life and his future (Kübler-Ross, 1978). Through drawings, the child provides a glimpse of his inner world, his attitudes, his behavioural characteristics and his personality strengths and weaknesses. The degree to which inner resources are used to handle conflicts is revealed. Drawings employ the language of symbolism and tap primitive layers of the personality. Through drawings of recollections of dreams and fantasies, the dying child can observe changes which occur in himself and may be encouraged to discover for himself the meaning of his productions, often through free association. In an atmosphere of acceptance, the dying child draws or models what he does not dare put into words. Moreover, he cannot deny his drawn images. However, the psychologist may make interpretive deductions only in the context of other information to help him understand the child and care for him more adequately (Schaefer & Millman, 1979; Lewis & Greene, 1983; Di Leo, 1973).

4.4.3.2 Music

Throughout the ages, people have observed and, sometimes, used the healing powers of music. Music has a very personal and intimate meaning for each individual, a fact which demands a great deal of respect. It is important

to stress the need for careful assessment in the introduction and application of music with each child because people often have little defence against the influence of music, and the impact often has far-reaching, emotional and psychological effects which need to be observed and channelled appropriately (Munro & Mount, 1978). A variety of musical instruments can be used, both in performing for and with the patients. Records and tapes may also be useful. A competent psychologist's discussions arising from the musical interaction could therapeutically be used to the benefit of the child. While listening to music, the child may use other means of self-expression, such as making collages, drawing or sculpting. Music can also be used most effectively when the child is extremely anxious, very withdrawn, has intractable pain, or has difficulties with interaction.

According to Sears (1968), music therapy is a highly developed system for stimulating and directing behaviour for the purpose of achieving clearly delineated therapeutic goals. Music demands, in a non-threatening way, behaviour that is time ordered, reality ordered, ability ordered, and affect ordered. It concerns a person's attitudes, interests, values and his meaning towards himself, and it provides an opportunity for self-expression and the gaining of new skills which enhance self-esteem. In this way, it provides satisfaction and an experience which is safe, good and pleasurable. Music also provides an opportunity for group encounter, in which a person will make contact with intense feelings which he may choose to share in a socially acceptable way.

The author worked with two different terminally ill adolescents who loved music, and who were able to use it most effectively to make contact with their feelings. Music helped them to relax and to cope with pain and

progressive physical deterioration. The last wish of one of them, before he fell into a coma, was for the music of Bach to be played in his room until after his death, and after his parents had said their goodbyes and left his body.

4.4.3.3 Play

Play is the child's natural medium of self-expression. It is an opportunity given to the child to "play out" his feelings and problems, just as, in certain types of adult therapy, an individual "talks out" his difficulties (Axline, 1969). Thus, play may offer the child a means of counteracting the assault of the fatal illness upon the integrity of his self-image. Play activity can help the child to reaffirm his identity and, simultaneously, help him to express and master specific feelings related to, and associated with, his illness and treatment. The focus of these anxieties may vary in accordance with the developmental level of the child.

Therapeutic play can release anxiety, both prior to and after painful procedures and in the face of other crises, including impending death.

By means of play, a child can establish with the psychologist an immediately pleasurable, meaningful, and reciprocal interaction. As a result, trust and hopefulness evolve. In play, the dying child can displace fears into fantasy and, by using repetition as a means of working through conflicts, strengthen his adaptive ego mechanisms. Therapeutic play facilitates the identification of misinformation, positive and negative thoughts, and deep concerns. Communication to the psychologist via free association in play may form the basis of exploration of fantasies and unconscious motivations. Details of traumatic circumstances can be played out and anxieties can

gradually be overcome.

If a child has the emotional strength and security to feel and to show his anger, he can be helped in a play situation to use this resentment productively, for example by pounding a pegboard, splashing paint on paper, banging toy cars together, or beating a pillow. When play can be provided as a means of communication and emotional release in the context of insight into the dying child's feelings, thoughts and behaviour, staff can plan efficient care to meet the child's needs more effectively (Easson, 1970; Pfeffer, 1979; Schaefer, 1979; Adams, 1984).

4.4.3.4 Storytelling, Poetry and Puppets

4.4.3.4.1 Storytelling

Eliciting stories is a time-honoured practice in child psychotherapy. From the stories told by children, the therapist is able to gain invaluable insight into a child's inner conflicts, frustrations and defences. Gardner (1979), in his "mutual storytelling technique", first asks the child to tell a story. The therapist then tells his own story, using the same characters which the child has used, but offering a better solution. Since the child's story is projective, it will generally reflect something about the child's experience of his life situation. Each story is ended with a lesson or moral, derived from the story situation. When using this technique, it is important to know something about the child and his life, in order to understand readily the main theme of the child's story. The psychologist could also begin a story and ask the child to end it, or the child may begin it and the psychologist may end it. Sometimes the child and the psychologist can make up a different ending to one which they read

together.

The use of telling a story to young children in distress, about a child in similar circumstances whose needs were met, has been described in a previous section.

Children find it easy to identify with characters in fairy tales, probably because of the basic universal emotions involved: love, hate, fear, rage, loneliness and feelings of isolation, worthlessness and deprivation. With the help of the psychologist they may be able to verbalise these feelings themselves as they identify with the fictional characters.

4.4.3.4.2 Poetry

Poetry is said to from the heart. What this means is that, in the form of a poem, thoughts and feelings which might otherwise be difficult to share in ordinary talking and writing may be expressed. In poetry, the child may release emotions freely, even crazily. The psychologist may read selected poems and ask the dying child to close his eyes and allow himself to absorb the poem. When the psychologist has finished reading, the child may be asked to draw a picture of his feelings about the poem, or the psychologist and the dying child may write a poem together, each one offering a line.

4.4.3.4.3 Puppets

It is often easier for a child to talk through a puppet than it is for him to say directly what he finds difficult to express. The puppet provides

distance, and the child feels more secure in revealing some of his innermost thoughts in this way. With younger children, the psychologist may talk to the child through a hand puppet. Children often respond far more quickly to the puppet than to the psychologist (Oaklander, 1978; Robertson & Barford, 1979).

4.4.3.5 Dreams

Dreams unquestionably play a major role in adult analysis. Children have good dreams and nightmares, and the psychologist needs to be aware of the dreams of a dying child. Dreams should not be interpreted, but they can be used as a springboard for discussing everyday events and feelings. A dream may also help the psychologist to clarify or confirm themes which could be used in play or in fantasy exercises.

Children who recount disagreeable and frightening dreams usually communicate severe anxiety in their waking, as well as sleeping, hours as their weak, overwhelmed egos cannot handle excessive stimulation. Because interpretation would bring them too close to frightening material, it is preferable for the psychologist to rather empathetically reflect on their effect. Treatment gains, i.e. a strengthened ego and improved functioning, generally bring about more relaxed sleeping patterns. The non-interpretive, reflective approach is based on greater respect for the defences of the ego. Thus, the psychologist should careful not to delve into the primary process to reveal the threatening content of the dream, in his dealings with the dying child in the context of psychotherapy (Young, 1974; Mishne, 1983).

4.4.4 Pets

When the entire world seems to disintegrate around a child, a pet may serve a very therapeutic purpose, sharing the grief and anxiety with the child, and offering hope. The child may entrust his grief, tears, fears, terrors and guilt to a pet, as the pet's non-demanding acceptance of the child's hidden emotions and his unfailing admiration and love for the child, are most comforting. The pet may represent a protector against the fear of death. The psychologist may encourage parents to give the child a pet during remissions and his stay at home (Levinson & Kinney, 1974).

4.4.5 Touch

The simplest and the most significant of the humanistic measures contributing to the relief of pain, and providing a feeling of security and belonging in children, is touch - the ancient rite of the "laying on of hands".

To sit or stand quietly at the dying child's bedside, perhaps holding his hand, can offer more support and evidence of concern than can words. For the dying child, touch means comfort and contact; it means the assurance that he is not alone, and that appearance does not matter. However, the psychologist needs to be sensitive to how much contact a child wants. Some children may resent being touched, because of physical pain which it may cause. Other children are emotionally withdrawn and isolated, and do not want physical contact. The psychologist can quickly assess how withdrawn a child is by using fingerplay, making a game of walking towards the child with his fingers. From the child's reaction, one can determine whether or

not physical touch is desired, and the child's preference should be respected (Bushman, Sheets & Wharton, 1973; Young, 1974).

4.4.6 Groups

Dying children often derive strength from the group situation. In the group, identification can easily be established, as children who find the verbal expression of anxiety or other feelings quite difficult in individual situations, may empathise with fellow patients. The other children would then verbalise their feelings for them.

Grouped together, dying children realise that theirs is a common lot; that all of them have to submit to the same, or similar, restrictions; that most of them, for the time being, cannot move around and that all of them are in the hospital to be cared for.

The purpose of these groups is mainly supportive, and the psychologist should be reticent in making interpretations. At times, other media, e.g. paint, modelling clay, etc., can be used to facilitate self-awareness and self-expression. The psychologist will find much support in working with a co-therapist and the children will benefit because both therapists can share impressions after the sessions, and thus provide much needed support for each other (Kübler-Ross, 1976; Gibbons, 1974; Kraft, 1971).

4.4.7 Relaxation

The use of relaxation techniques (Wolpe, 1973) is another approach to be considered in supporting and caring for terminally ill children. Generally, this involves concentrating on comfort measures and attempting

to consciously relax and contract alternate groups of muscles, thus providing a feeling of physical comfort and even relief from pain, if this is present. Patients will also experience a feeling of mastery and control over their bodies.

The psychologist must assess the patient's ability to relax before using this method. This will depend partly upon evidence of the degree of calmness that relaxation brings about in him, and partly upon impressions gained from observing the child (Graner, 1976).

4.5 CARING DURING REGRESSION

Especially as he approaches the end of his life, the fear of regression becomes a reality for the dying child. With diminution of physical capacity and clouding of consciousness, the sense of regression may be frightening and the child may fight against it trying to hold on to the concrete, hard, reality-bound consciousness of himself.

The psychologist can help the child shift away from reality and turn inwards to the self, thus allowing withdrawal and regression to occur. The dying child may be able to accept the caring of his parents and the staff if this is warm, genuine, kind and comforting. He may now be able to allow himself to be babied and comforted, as long as no-one threatens his self respect by treating him as a child, inferior to them. Emotionally, he is no longer functioning as a proud, emancipated person, but he must still be respected as a person (Easson, 1970; Pattison, 1977).

4.6 CARING DURING THE FINAL HOURS AND UNTIL DEATH

There should never be a point, however close to death, when it is thought that nothing more can be done for a child. When active treatment has ceased, there must be continuing activity around the child, regular efforts to make him comfortable, and availability of trusted people, so that he is encouraged to talk when he so wishes. During the routine services in the ward, his bed should never be excluded. On the contrary, more time should be spent with him so that he has no sense of isolation. A dying nurse expressed her needs as follows:

"I am a student nurse. I am dying. I know you feel insecure, don't know what to say, don't know what to do. But please, believe me, if you care, you can't go wrong. Just admit that you care. That is really for what we search. We may ask for whys and wherefores, but we don't really expect answers. Don't run away - wait - all I want to know is that there will be someone to hold my hand when I need it. I am afraid. Death may get to be a routine to you, but it is new to me. You may not see me as unique, but I've never died before. To me, one is pretty unique. You whisper about my youth, but when one is dying is he really so young anymore?"
(Anonymous, 1970).

In the presence of death, the child may become concerned with resolving conflicts from the past, and finding rapid solutions to any conflicts which emerge from moment to moment. Some children may hang on to life because of unfinished business. The psychologist must be aware of this possibility, and may ask the child directly about things that may be worrying him. Children also need the emotional permission of their parents to die. Once this is clearly granted, verbally and non-verbally, the child can let go and die in peace.

An example of the successful negotiation of a peaceful and dignified death was witnessed by the author, who attended to an eleven year old boy dying of a malignant brain tumour. After cure-orientated therapy was

discontinued, he realised that he was dying, and talked openly to his parents about it. He stated categorically that he would never be able to die in hospital, although he loved the nursing staff, and asked that everything possible be done to take him home. This was done. Already weak and very frail, he asked his friends to visit him. Gathered around his bed, he gave each of them something very personal. One received his cricket bat, another his rugby ball, yet another his tennis racquet. He thanked them for their friendship, and said goodbye to each one separately. A few hours before his death, in the early hours of the morning, he became remarkably alert, looked at his mother who was sitting at his bedside and holding his hand, and told her that he knew that she would miss him very much once he was dead. He would like her, when she was ready for it, to have another baby, because she was the most wonderful mother in the world. Soon afterwards he slipped into a coma, and died peacefully a few hours later.

4.7 THE PSYCHOLOGIST'S ATTITUDE AND BEHAVIOUR IN RELATION TO THE DYING CHILD

In summary, the following guidelines should be followed when dealing with the dying child:

4.7.1 Permission must be obtained from the parents before therapy with the dying child is initiated.

4.7.2 Knowledge about physical illness, the expected effects of

medication and the potential usefulness of anti-depressants and anxiolytics, is vital.

4.7.3 Attitude towards the Child:

- (a) A strong therapeutic relationship must be established, characterised by trust, empathy, genuineness and respect. Empathy is sometimes a natural gift, but can be acquired, for example by trying to imagine different ways of looking at the same situation, picturing various feelings towards the same set of facts, or imagining oneself in the patient's place.
- (b) There should be no hidden messages, no "shoulds", no pre-set goals. Rather, the psychologist must listen, show concern, offer help in the communication process, and tolerate negativism.
- (c) The child should be encouraged to take the lead. This may be prompted by asking if he has any specific questions, worries or concerns which he would like to talk about. Only open-ended questions should be asked. These questions should be backed by sound evidence of interest and immediate availability, such as sitting at the bedside and making eye contact. Asking perfunctory questions while standing in the doorway - obviously hoping for negative replies and eager to get on with other business - is both unresponsive and discouraging.

- (d) Forbearance may be rewarding. This involves respect for a patient's reticence and resisting any impulse to hurry the therapeutic process.
- (e) If a choice is called for, activity should be chosen above passivity, but the patient should then be allowed to follow the psychologist at own his pace.
- (f) The optimal attitude towards the terminal situation is one of compassionate objectivity. A psychologist who is stringently clinical is more of a technician than a therapist. On the other hand, being overly sympathetic distorts as much as being overly rational and objective.

4.7.4 Necessary Skills

- (a) Clarification is important, even if the meaning seems obvious. "For instance?" "I'm not clear ...", "In what respect?" may provide more exact information, but more important, may also evoke an emotional response.
- (b) Paraphrasing should be used to increase understanding, but not to prate without feeling. Mere chatter should be avoided by trying to measure or rank what is most relevant, real or uppermost. Example: "Who is your best friend?" or "What bothered you most about that?" or "How do you feel now compared with, say, last week?" Tentative suggestions may draw out a reluctant patient, even to disagree. "Perhaps I'm wrong, but you seem to want to be by yourself as much as possible?"

- (c) Potential distress should be rephrased more tactfully: "Not everyone has the courage to admit being anxious or afraid. What has it been like for you?"
- (d) Constant self-monitoring means that the psychologist asks questions, but should also know the value of silence. On the other hand, the psychologist should not duck behind a screen of silence and anonymity.
- (e) Confrontations must be timed to meet what is relevant to the moment. It has been suggested that in all dying patients, the concern about death be made the focus of the therapy, and that the task of psychotherapy is to subdue irrational fears, feelings of failure and wishes for punishment associated with death (Rheingold, 1967). The psychologist should not rush to talk about death or to underscore the gloomiest side of the illness, nor should he persist with empty optimism when facts no longer justify this. On the other hand, the psychologist should openly and dispassionately permit patients to talk about what is happening to them. A child who seems concerned about death should be asked what it is about dying that he fears. The psychologist must not be afraid to persist gently, but when the child becomes distraught and closes off, the matter can be left to be retraced in another way at a later stage.
- (f) Simply putting his feelings into words can diffuse much of the anxiety for the child. Concerns which he harbours may not be appropriate to the situation.

- (g) The psychologist must clarify often, interpret seldom, and never conjecture. Examples: "You felt as if there was no-one to turn to" (clarification).

"You didn't let anyone know how worried you were because you were afraid to get things out in the open and hear what you didn't want to hear (interpretation).

"You want to hear only good things, especially that everything is all a mistake, and that nothing has happened at all" (conjecture).

- (h) Signs of introgenic distortions and psychosocial complications which the terminal situation creates must be recognised. False hopes, displacement of interest to the illusory or to the trivial, withdrawal of personal concern and premature burial are but a few signs of introgenic problems (Weisman, 1979; McKittrick, 1981; Weisman, 1972; Lipton, 1978).

- 4.7.5 The psychologist must remember that schematic stages (Kübler-Ross, 1969): denial, anger, bargaining, depression, acceptance, are at best approximations and, at worst, obstacles to individualisation.

- 4.7.6 The psychologist, in wanting a dying child to want to live, will interfere with the child's dying trajectory.

4.8 CONCLUSION

The psychologist who works with children in a catastrophic situation may find to his surprise that there are real rewards in the work, which may not

have been anticipated. This work involves a new level of seriousness and profundity of feeling. Thus little effort or time is spent on the superficial, the petty vanities, the superstructure of life. Instead, the psychologist addresses the interplay of strong relationships and the power of transference and counter-transference. Furthermore, the psychologist will discover something which is rarely mentioned in text books on psychology and psychiatry - he will clearly see the strength and dignity of a human being, the deep altruism and the positive qualities that exist at all levels of personality, especially in children. Working with dying children increases one's respect for them, and makes one proud of being human being (Le Shan, 1969).

4.9 THE CLINICAL PSYCHOLOGIST AS THERAPIST

Working with a dying child is a very special kind of intervention, and would seem to require special approaches and skills. The primary goals of the clinical psychologist may be to help the dying child achieve a better death, "an appropriate death", and to help the members of the family to deal better with their loss, especially to forestall psychopathology during and after the terminal illness.

The clinical psychologist's interactions with the child and his family contain typical elements of rapport building, interviewing skills, history taking, psychotherapy, silences, etc., but in another sense this form of intervention is totally different. It involves helping a child deal with his own approaching death and this demands unstructured contact between person and person; something usually beyond the professional role and different from any other therapeutic exchange.

No matter how confident a clinical psychologist may be of his competence, when he becomes involved with the care of a dying child he must prepare himself for a difficult and emotionally taxing experience. In some respects, the clinical psychologist is particularly vulnerable since he is trained to perceive and respond to the nuances of the child's and parents' emotional experiences. He must be more than a technician, mechanically performing his duties; he must be another human being - available, loving and empathetic. Transference and counter-transference may be intense, and different from that experienced in any other therapeutic encounter, for the psychologist can love the dying child and allow the dying child to love him in a meaningful way, which is not possible in ordinary professional work. Too readily, however, empathy may merge into identification with the dying child and the grieving parents, and the psychologist may begin to grieve as though it were his own child who is dying. He may experience unaccustomed anxiety about his own children. Grief associated with significant losses in his past may be re-experienced and, in addition, the psychologist is confronted with the reality of his own finiteness and death.

This section deals with some of the qualities needed by the clinical psychologist in working with a dying child and his family, some of the pitfalls he may wish to avoid and, finally, some suggestions for taking care of his own needs.

Apart from his training as a clinical psychologist, further studies in basic thanatology and skills in caring for the dying are required. Knowledge about death is to be found in a wide range of publications on psychiatry, psychology, sociology, anthropology and social work. Many psychological factors influence the psychologist's ability to care for a dying child. The feelings aroused in him by dying persons, his attitude

towards dying and death, and his often subconscious defence mechanisms, all play a part. For this reason, some degree of self-knowledge is essential. It is also most important to carefully scrutinise his motives for getting involved with dying children. There may be a need to solve personal, sometimes neurotic problems, which may be deep-seated guilt, or previously unresolved grief reactions to a loss experience, a passion to proselytise people to own world views, or a wish to prove that he can deliver better care than that received by a relative of his own.

Some experts insist that one cannot help another person with death-related concerns unless one has first come to accept one's own mortality. This seems unrealistic. The majority of people find it very difficult, if not impossible, to reconcile themselves to their own death. To be effective, however, the psychologist should be in the process of personal confrontation with death and from time to time reflect upon, and clarify, his concepts, beliefs and attitudes about death. He should acknowledge his own mortality, and work on a philosophy of life - which certainly includes the possibility of death and what happens after death. This may enable him to overcome some of his own anxieties and not be too uncomfortable when talking about the subject. However, no psychologist should underestimate his vulnerability and tendency to deny. Furthermore, flexibility is essential for the clinical psychologist working with a dying child, as to use a fixed system would be to misconstrue the art. The goal is always to make the limited time the child has left as bearable, meaningful and self-fulfilling as possible. This, naturally, calls for maximal flexibility within a framework of basic security.

Other areas where self-knowledge is of major importance are the psychologist's anxiety tolerance, his guilt feelings, his ability to cope with

anger and his positive desire for omnipotence. Contact with a dying child inevitably arouses the psychologist's own anxiety over illness, suffering, death, and the transience of life. The strain may be considerable at times and psychologists with marked death-anxiety which is easily aroused should refrain from becoming involved with the caring of dying children. It would, however, be unrealistic to propose that this work should be reserved for psychologists with no death anxiety. It is wishful thinking to suppose that death anxiety can be completely eliminated by psychotherapy, neither does this seem particularly desirable. It is important to remember, though, that the psychologist will never be in a position to allay the anxieties of others if he does not try to understand and handle his own.

Suffering often generates feelings of guilt in others. The psychologist may feel guilty about the health which he still enjoys and the fact that he eventually will survive; about his inability to fully understand; about the fact that he cannot lead the way; about the fact that his therapeutic intervention is less than completely successful. If he wishes to support the dying patient, he must attempt to work through these feelings and, if possible, dispose of them once and for all, for a dying child may engender such guilt feelings that, in order to save the psychologist and retain the contact, the child may conceal his own anxiety and avoid talking openly about his experiences. It involves a conscious effort on the part of the psychologist to realise and eventually convey, using verbal and non-verbal messages, that he is not guilty or responsible for the patient's suffering, pain, anxiety and eventual death.

Guilt, being an unpleasant feeling, may produce feelings of anger towards the child who caused the guilt and a self-sustaining emotional chain reaction may begin. Death is a threat to the psychologist's feelings of omnipotence, and working with a child who does not respond is difficult.

Becoming angry is a common substitute for depression and it is possible that the psychologist may become overly critical of colleagues or family members, projecting his anger onto them.

The psychologist may feel a need for omnipotence. It is, however, necessary to be on the alert for this, constantly questioning one's motives and being as candid as possible about working to correct behaviour which serves oneself, rather than the child. The reaction of over-protectiveness is common amongst psychologists working with dying patients and is often accompanied by over-indulgence. The psychologist repeatedly has to check himself with regard to all such feelings.

It would seem that if clinical psychologists are required to provide support, they in turn need to be supported. The psychologist, in working with the dying child, moves beyond the normal relationships which result from the human encounter. He is obliged to expose more of himself in the process or, conversely, must employ more vigorous defence mechanisms. Therefore, the psychologist has special needs which must be faced and resolved, in order to do his work adequately. Even skilled therapists, who work extensively with the dying, find that they come to feel used up - drained of their inner resources. For this reason, the clinical psychologist who works with dying children must establish a therapeutic relationship within which he can restore himself, face his own fears and inadequacies, and move beyond them by examining his own dreams and fantasies and discovering his own subconscious motives and drives.

The involvement in a support group would not only provide for the need to talk about emotional and physical problems of patients and families whom he is trying to help, but would also provide an opportunity to share his own

feelings about what is happening to and within himself.

Furthermore, to remain effective, the clinical psychologist must contain his emotional responses within endurable limits, and must maintain clear psychological boundaries between himself and the dying child. Such processes are fostered by regular reviews of the work with a supervisor, experienced colleague, or psychiatric consultant. Such review is helpful to the psychologist in developing a high level of self-awareness concerning the nature of his responses to the tragedy, the sources of his feelings and attitudes to it, and his own resources and potential which enable him to deal effectively with the dying child and his family (Feigenberg, 1980; Glaser & Strauss, 1974; Grof & Halifax, 1977; Leveton, 1971; Lipton, 1978; McCollum, 1974; Parkes, 1978; Rothenberg, 1974; Saunders, 1969; Schowalter, 1978; Shneidman, 1974; Weisman, 1977).

Based on observations in a hospital devoted to cancer care, Harper (1977) concluded that continuing involvement with the dying and the bereaved is a traumatic experience for health professionals, and that anxiety is a major factor in their attempts to cope. She observed that professionals experience a process of cognitive and emotional change in learning to be comfortable with death-related tensions and experiences. She proposed a model incorporating these psychological changes into a normative sequence of development experienced by workers as they gain in knowledge and understanding, and move toward maturation in coping with death and its associated conflicts. The model in Figure 2 shows the stages of emotional and cognitive change as steps in the development of an adaptive capacity to cope with the stresses of death. Furthermore, Harper emphasised that the worker-supervisor relationship and basic support received from his environment contribute significantly to the worker's growth (Benoliel, 1981).

FIGURE 2 : The Stages of Emotional and Cognitive Change

STAGE 1 1-3 months	STAGE 2 3-6 months	STAGE 3 6-9 months	STAGE 4 9-12 months	STAGE 5 12-24 months
<u>INTELLECTUALISATION</u> Knowledge Anxiety	<u>EMOTIONAL SURVIVAL</u> Experiences trauma	<u>DEPRESSION</u> Experiences pain Mourning Grieving	<u>EMOTIONAL ARRIVAL</u> Skills Moderation Accommodation	<u>DEEP COMPASSION</u> Achieves self- realisation Awareness Self-actualisation

In summary, the psychologist, in making himself available to work with dying children, will discover that terminal care is costly in terms of time, energy and emotions. He will discover that he has embarked on a route which cannot be continued without a willingness to be open and to grow as a person and as a professional. He will discover how he manages his own anxiety in the presence of the dying. He will experience guilt about his own health, and frustration and anger because of the slow, incapacitating process of dying. He will experience grief and depression and will begin to question his own usefulness and ability to contribute and be helpful. However, in time, with resolution of the above feelings, he will experience a feeling of freedom, and will no longer be pre-occupied with his own death, guilt feelings and depression. Not free of pain, but free from its incapacitating effects. Being free, he will respond emotionally to the dying child in an appropriate way. Eventually his behaviour and performance will be enhanced by the dignity and self respect he feels for himself, and this will enable him to give dignity and respect to the dying child.

The psychologist will discover the value of colleagues, friends and his own family; he will realise that he cannot do this work in isolation and that he needs the support and love of people around him. He will learn to take care of himself; to be kind to himself and, above all, his work with dying children will become a most meaningful endeavour.

CHAPTER 5

THE REACTION OF THE FAMILY TO THE TERMINAL ILLNESS

AND DEATH OF A CHILD

Just as the family is the unit of living, so it is also the unit of illness and sometimes of dying, for it is within this framework that all family members experience most deeply those events in life which involve beginnings and endings, unions and separations, and the many emotions engendered by such events (Atkin, 1974).

According to Wiener (1971), there is no more devastating experience in the life of a family than the fatal illness and death of a child. It tears into the family's life as a functioning unit, and confronts each family member with a crisis in coping with loss and grief. The shock extends from parents and siblings to involve grandparents, other family members and friends.

This chapter elaborates further on the family, its problems, perceptions and interactions with regard to the terminal illness and dying of a child. It focuses on the effect which the loss of one of their children, or their only child, has on the parents, their marriage and on each individually. The siblings' reactions to the death of a brother or sister, and the reaction of friends to losing a playmate and possibly a lifelong "buddy" will also be described.

5.1 THE FAMILY

5.1.1 Introduction

Urban industrial society has intruded forcefully on the family, taking over many functions which were once considered the family's duties. The family which must always accommodate to society is changing with it. There are no external verities as values or systems of beliefs, as well as the

roles played by the family members, are at present changing - more rapidly than ever before. As people moved from the farm to the city, the extended family and elaborate kinship ties gradually gave way to new values of family living. The nuclear family, living in its own home and making its own decisions, became the ideal. Perhaps in the best form, a small, nuclear family with its members concentrating their effects on each other, allows maximum loving to emerge and provides deep feelings of importance, if not omnipotence, in the few involved (Krant, 1974b). The smaller the family, the more concentrated the emotional influences of the small number of people involved will be.

The loss of a family member, especially in our modern society where families are small and the emotional investment in each other intense, may be the single most upsetting and feared event in the life of a family (Kalish, 1977). The family is part of the individual, and the individual is part of the family. No terminally ill child is an island, alone in his suffering. As through one relationship or another, he is tied to other individuals, and what disturbs him creates problems and difficulties for many people comprising his circle. Like a pebble thrown into water, illness causes ever-expanding circles, affecting not only the person who is ill, but also his family, which is called upon to meet many of the emotional and physical costs of the illness. Therefore, every patient must be viewed, that is, diagnosed and treated, in the context of his family setting (Feldman, 1974; Field, 1967).

The family itself is a viable entity, a system which is constantly changing, sometimes slowly, sometimes rapidly. It is a system which is delicately balanced and struggles to maintain that balance, or homeostasis.

The system is made up of subsystems, and a change in one part changes the balances of the system.

According to Minuchin (1974), the family is a social unit which faces a series of developmental tasks from the beginning of its existence, i.e. from marriage. The couple needs to accommodate to each other, separate from each other's family of origin, and negotiate different relationships with parents, in-laws and friends. The birth of a child marks a radical change in the family organisation. The physical and emotional commitment to the child usually requires a change in the spouses' transactional patterns. A new set of subsystems appears in the family organisation, with children and parents having different functions. This period also requires a renegotiation of boundaries with the extended family and the extra-familial. The functioning of the spouse unit must be modified to meet the demands of parenting.

Over time, the family develops patterns of interaction. These patterns make up the family structure, govern the functioning of family members, delineate their range of behaviour, and facilitate their interaction. A viable form of family structure is needed to perform the family's essential tasks of supporting individuation of the children, whilst simultaneously providing a sense of belonging.

When a family discovers that a child is terminally ill, both strengths and weaknesses in the family structure may be exaggerated. Perhaps nothing reflects family stability and integration so much as the way in which the challenge of the diagnosis and treatment is met (Burton, 1974b). A study by Strauss (1975), and quoted by Anglim (1976), cited a 50% break-up through divorce and separation of families which had a terminally ill child.

Weisensee (1976) estimates that because of the stress involved, up to 80% of parents with a leukemic child will eventually divorce. She quotes Kaplan (1973) who studied families of 50 leukemic children. Within three months after the child's death, 39 families were reinterviewed. Of these 39, 18 had divorced or separated after the child became ill, and marital problems became exacerbated for 11 others. In 14 of these families, surviving children had difficulty, and four of them were placed outside the home. Preoccupation with the surviving children's health was noted in 12 families. Unresolved grief, reflected in behaviour such as going to the cemetery daily, preoccupation with the deceased child in conversation, complete avoidance of the subject, or "shrine building", was admitted by 27 parents. Drinking problems surfaced in 14 families; 8 sought psychotherapy for the first time, and six had psychosomatic complaints such as ulcers. Problems at work were encountered by 14 parents, and 6 children had serious difficulties at school. While family dissolutions may be on the increase in general, this high rate is indicative of the degree of stress to which families are subjected under these circumstances.

Because all family members are sensitive to each other's feelings, and everyone in the family is aware that the other has feelings, the distress experienced by one person is felt by all. However, because of the family's attitudes of protectiveness, the individual in distress attempts to hide his problems from others. This is often seen in children, too. In doing this, a child prevents other family members from assisting him with his problems, and also prevents the resolution of the feelings which they share with him. Thus the attempts to protect may actually increase suffering.

When the dying child changes his customary role, the whole family is

required to make adjustments, and such a change in established patterns usually proves difficult to a family which naturally strives for stability. The reallocation of tasks which were performed by the terminally ill child, now hospitalised and removed from the family, is often left to be settled by default, with often no clear decisions made about how they should be done and by whom. Often there may be a reluctance of siblings to take on any part of the terminally ill child's role. In an extreme situation, this may even mean disposing of a much-loved pet.

Sometimes after lengthy hospitalisation, re-organisation takes place within the family, with new patterns of relationships established in order to fill the gap vacated by the patient. This may succeed so well that subsequent problems arise when the patient goes into remission and returns home (Verwoerdt, 1966).

The reactions of the family to the terminal illness of a child will be determined by each member's own attitude to illness, the importance which the deprivations imposed may have for him, and how long these deprivations have to be endured. Most important of all is the feeling that they have about the child and the place which he holds in the family group (Field, 1967). Other determinants in the family's reaction include the suddenness of the illness, the length of the illness, the amount of suffering experienced by the patient, and the stability of the patient and his family (Heimlich & Kutscher,, 1971). Other variables, such as culture, religious background, life style, and past life experiences, personal as well as with the disease of their child, are factors colouring the familial reactions (Barbero, 1971).

Reactions which may range from adaptive to temporarily disruptive, to more

severely maladaptive, may occur in each individual and in the family as a unit. Each family member is affected in a way which represents his previous adjustment (Wiener, 1971). Heimlich and Kutscher (1971) stress the fact that the younger the patient, the greater the effect of death on the family.

The family, upon learning of the terminal diagnosis of one of its members, generally reacts by denying the seriousness of the situation in order to maintain not only their own security, but also that of the family unit (Carlozzi, 1968). According to Maddison and Raphael (1972), communication patterns within the family of a dying patient are frequently modified, decreased, or accentuated in pathological and pathogenic ways. The "conspiracy of silence" about the prognosis is one particular instance of this, by means of which the patient and the family may be denied the opportunity of working through their anxieties, sharing their remaining pleasures, and planning realistically for the future.

Hamovitch (1964) found that the poorer the prognosis, the more difficulty the family has in coping with the illness experience. This was confirmed by Spinetta (1978), who found that in families where communication with the child was open, the child was able to communicate both happy and painful feelings and anxieties.

Krant (1974b) points out that supportive, loving and intimate relationships between family members occur often enough, but there would appear to be a rather high percentage of families where collusion and scapegoating exists, or where ambivalent relationships are common. When a fatal illness develops in such a family, members become engaged in protecting themselves or hurting others, rather than openly supporting each other. Thus, an

ambivalent position with regard to support and self-protection frequently develops. The ambivalent feelings may not be present in the early days of a fatal illness, when all energies are exerted to find appropriate help through medical diagnosis and treatment, but, as the disease process drags on and easy solutions to many emergent problems do not appear, strains and stresses are placed on family members which can promote exhaustion, impatience, anger and a sense of futility. The sense of duty and obligation frequently weakens, and various members begin to withdraw from the patient, claiming that there are legitimate, pressing needs of their own which occupy their energies.

5.1.2 Emotional Reaction to the Terminal Illness of a Child and a Sibling

As previously mentioned, reaction to the news of terminal illness in a child or sibling may range from adaptive to temporarily disruptive, to more severely maladaptive. Each parent and sibling reacts to fatal illness individually, in a manner consistent with his own personality structure, past experiences, current crisis, and the particular meaning or special circumstances associated with the loss threatening him. However difficult it may be to generalise, an attempt will be made in this section to identify some of the major emotional reactions which a family may experience during the terminal illness of a child and sibling.

5.1.2.1 Shock

Nothing is worse for a family than to learn that their child is suffering from a terminal illness. There is no doubt that the diagnosis of terminal illness represents a severe blow to the parents and the whole family. The

diagnosis often brings some relief because it ends the uncertainty about the illness, but the feelings of relief are often mixed with those of anxiety, fear, depression, guilt and anger (Kulczycki, 1971). Frequently there is an initial sense of shock or being stunned following the diagnosis, even though family members may have sensed what was happening for a long time. This period of shock may be only momentary or may last for several days or weeks, during which time the members of the family may seem dull and without any real feeling. They may sit in stunned silence or in numbed grief. They may cry, become upset, and often say openly, "It is too much to understand." This is a defensive reaction on their part, enabling them to gradually assimilate the meaning of the illness. Green (1967) points out that overwhelming anxiety may make it difficult for parents to attend to discussions about the disease, impair their judgment, and limit their active participation and caretaking competence.

If all members of the family were not involved in the initial announcement of the diagnosis, and parents begin to conceptualise the contents of the doctors' words, they may wonder how to convey their sad news to other members of the family. While some may inform relatives at once, others prefer to defer this task until they, themselves, have begun to sort out their own feelings (Atkin, 1974).

It must be emphasised that even young children are sensitive in picking up, from verbal and nonverbal cues of parents, the message that something serious is wrong with their sick brother or sister. Because of the small size of the nuclear family and the often intense emotional involvement of members with each other, almost nothing can be kept from other family members. Furthermore, through popular magazines and television programmes,

children are frequently exposed to, and knowledgeable about, the variety of illnesses from which children die.

Some parents are aware of the paucity of their emotional reactions, frequently explaining this on the grounds that they "could not break down" in the presence of the children or their physicians. Their uneasiness about their apparent lack of emotional expression is suggested by the fact that parents will occasionally verbalise their confusion, and possible guilt, over not feeling worse (Friedman, Chodoff, Mason & Hamburg, 1963).

Family members must first adjust in their own way to the threatened loss, and then to the actual death of a child or sibling. The nature of the adjustments reflects, to varying degrees, the parents' manner of coping with past crises, previous experiences with illness and death, and the meaning of this particular child to them (Green, 1967). Once the "diagnostic family crisis" is over, there is continuous concern related to the prolonged day-to-day care of the patient, who may suffer frequent relapses, frustrations and exacerbations (Kulczycki, 1971).

5.1.2.2 Anger

The family members feel anger and frustration at the loss they are experiencing. They are losing a relationship which has been meaningful to them both meaningfully positive and meaningfully negative. With good reason, they resent the fact that they are being made to suffer in this fashion (Easson, 1970). One word which best symbolises the anger of bereaved parents and siblings is "Why?" In our present age of declining religious belief, many parents are unable to see a divine purpose in the event, and they construct explanations from a composite of scientific facts, anecdotal

information learnt from others, and fragments from their own fantasies. The question, "Why did this happen to our child or our sibling", is not meant as a request for a philosophical explanation, so much as it is a rhetorical question which reaches for an emphatic response, an exclamation of anger at the injustice of an universe which can permit such seemingly senseless events. The clergy, the church, and God, may become targets of angry protests (Willis, 1981).

Anger and hostility may arise from several sources. The patient's disease imposes an emotional and economic drain upon the family. The normal flow of life and the family routine and activities change considerably or, in extreme cases, may be totally eliminated or restricted. Angry, hostile feelings may be related to feelings of guilt, futility and helplessness. Family members may become worried and guilty because they realise that they feel angry, even at the child who is dying. Logically, they understand that the dying child does not want to die, but they nevertheless find that they are angry towards him. However, since in most instances they do care deeply for the dying child, they do not vent their anger on the child who is going to leave through death (Easson, 1970).

Anger may arise because, despite everything the parents have done, the child fails to thrive, and this leaves the parents with all their own unfulfilled hopes and ambitions for him and, indirectly, for themselves (Burton, 1971). Parents may also feel cheated, and in anger they may wish the child had never been born, or would "just die and get it over with." They have trusted the doctor; they have sought the best help available. They have listened to hopeful comments about new treatment regimes and new medication, but to no avail. Even after they have acknowledged defeat in

exchange for a quick and painless death, after months and even years of endless fighting against the illness, they find that death in a modern hospital is often neither swift nor painless. Resentment and hostility towards the physician and the medical team may increase, as the parents blame them for their impotence in not being able to save the child and keep him alive. The longer these twilight hours and the greater the stress on the family, the greater the need for opportunities to discuss and ventilate their feelings (Lorin, 1971).

Anger and guilt are common feelings in siblings who must watch someone else occupy the centre of attention. Few people concern themselves with the well children when there is a terminally ill child in the family. Parents often panic at the least complaint of the dying child, even though it is sometimes obvious to the other children that the sick sibling is using his disease to get attention. The well children may even use the same complaints as the sick sibling, only to be rebuked for doing so.

Because the well child's state of mind is taken for granted and so much is demanded of him, he may not have the opportunity to express anger, or rid himself from guilt. Finally, his feelings may break out in a devastating catharsis: "I wish that brat would drop dead." The well sibling who hears someone caution him that "someday you'll be sorry you said that", knows it is true. Someday he will relive the guilt and shame, possibly many times over. Anger and guilt may be inseparable during the course of the sibling's illness, but after the death, guilt begins to predominate: guilt at being healthy, guilt at being the survivor when he may feel he is the more expendable of the two. Moreover, the child who once wished he were an only child feels that by some magical process he has made his wish come true (Gyulay, 1978).

Since few people can tolerate indirect, free-floating anger, it tends to be directed towards a significant object. Frequently the resentment is expressed towards other members of the family. Parents may attack each other in violent anger, subject each other to blame for the child's illness, or to reproach for their partner's response to the diagnosis and mode of coping with stress. Siblings of the patient may become objects of anger, perhaps readily selected because they manifest provocative, demanding behaviour in response to the family crisis. Brothers and sisters may be irritable and nasty to each other. Often bitter accusations are made - sometimes accusations that the child's illness has been caused or allowed through negligence within the family. Illogical, resentful statements can be made. Violent threats can be expressed - all because these family members care deeply, grieve greatly, and are angry because the dying child is leaving them. Sometimes sorrowing relatives turn their anger in on themselves and become severely depressed (Easson, 1970).

5.1.2.3 Guilt

According to Friedman, Chodoff, Mason & Hamburg (1963), clinical observation shows that guilt is common in relatives of seriously ill children. Parents tend to feel responsible, directly or indirectly, for whatever happens to their children. Once the diagnosis of terminal illness is made, the parents will almost without exception, initially blame themselves, for a variety of reasons. They may feel that they have failed in their most basic parental responsibility. This blame is inescapable and intolerable. They feel they have not known enough, or done enough, and because they have failed, their child is dying (Easson, 1977; Edelstyn, 1974).

Parents of a leukemic child may feel responsible for having passed "bad blood" on to the child. They wonder if the child's life could have been saved if they had spotted symptoms earlier and obtained medical help sooner. They may feel guilty of neglect. The sad father berates himself for giving the child a hiding the day before the diagnosis was made; the mother feels she has failed her child, perhaps feeling that if only she had fed him better he would have been stronger and thus could have resisted the illness. Parents often focus their guilt on having failed to spend more time with the child, or having postponed enjoying the child until it was too late. Brothers and sisters may feel guilty because they were not better protectors. The family, as a whole, feels increasingly worthless and bad.

At times, the family's guilt may stem from many troublesome, yet uncontrollable, thoughts that plague the inner consciousness. Perhaps the most disturbing thought for a family member to manage, in that he loves the dying person, is his feeling of "relief" that it is someone else who is dying and not himself (Bowers, Jackson, Knight & Le Shan, 1964). Other family members may feel guilty in a completely different fashion. Suffering pangs of guilt at being alive while the one they love so much is about to die: "If only I could take his place", is a commonly expressed sentiment. (Carlozzi, 1968).

The well child may feel guilty for having fun or making plans for the future. Even though he knows he is not responsible for his sibling's illness, the resumption of a normal routine may seem wrong and parents may reinforce this notion: "That's good. Such a pity your poor brother will never get to that. You have so much. He has nothing and is losing everything" (Gyulay, 1978).

According to Verwoerdt (1966), guilt feelings may spring from two types of situations involving the relationship between the family and the patient. On the one hand, the fatal disease may produce such a strain on the patient and his family over an extended period of time that the frustration, anxiety, and irritations, generated by the illness situation, begin to take the shape of interpersonal conflict. Relatives may grow short of patience with each other and with the patient, whose threshold of irritability is already lowered by his disease. The relatives may feel intermittently guilty and contrite over their irritable behaviour or hidden resentment, but since the basic situation remains unchanged and they continue to have the same frustrations and worries, the resentment is aggravated. In the second guilt-provoking situation, the relatives over-extend themselves in the care of the patient, to the point of exhaustion and subsequent resentment, as a result of which they may even catch themselves wishing it was all over. At this point they become ashamed of their impulses, and so resolve to put forth extra efforts to be considerate and helpful. This leads to further fatigue, strain and longing for relief, so that a vicious circle is set in motion.

As mentioned in the previous section, relatives often have very real, angry wishes towards the patient and may wish for the patient's death. These death wishes may occur frequently, and provide an additional source of anxiety and guilt (Warwick & Shapiro, 1971).

When a child must be hospitalised, pre-existing guilt in the family may cause them to interpret hospitalisation as their own rejection of him out of the home and the family. To make amends, they spend much time around the sick bed, trying to do all sorts of things for the child (Wiener, 1971). Parents, friends and siblings may feel the need to fulfil the

child's every wish, with ridiculous spoiling and a change in attitude towards money. Some children are given things appropriate to those who are much older, or taken out of their usual routine of life on extra outings or holidays. Parents may also become over-protective or over-indulgent, interfering with necessary diet or enforcing activity restrictions. They may become totally unable to set and maintain any reasonable limits on the child's behaviour, thus surrendering the parental role. On occasion, the whole family setting is changed as the child's father takes time off from work to be at home. Most of these things are not done to benefit the patient so much as to fulfil the deep needs of the parents, who may feel guilty and helpless in the face of this unthinkable distressing situation (Thompson, 1976; Wiener, 1971).

Feelings of self-blame are often unbearable for most family members so, in a very understandable way, they may try to make life tolerable for themselves by blaming others. If they can displace this blame, they will be able to live more easily with themselves. The father can still feel that he is a competent man and the mother can still cling to her self-confidence if someone else can be blamed. Because the parents need to shift blame to others, they may show seemingly illogical anger towards any person associated with the child. They need someone to relieve them of some of their intense guilt (Easson, 1977).

5.1.2.4 Anticipatory Grieving

Anticipatory grieving, as defined by Lindemann (1963), occurs when family members are so concerned with their adjustment in the face of potential loss, that they slowly experience all the phases of normal grief as they

cope with the illness, or endure the separation prior to death. Over an extended period of time, therefore, the family members may experience depression, feel a heightened concern for the ill member, rehearse his death and, finally, attempt to adjust to the various consequences of it. Prior to the actual occurrence of the death itself, the family will, to the extent that they have anticipated the death or dissipated their grief, display little or no emotion (Fulton, 1971).

As parents and family members realise that the death of a child is not only a possibility but a certainty, they begin to face the reality that the child will die. They anticipate the loss of a relationship which most probably has been extremely meaningful. With the realisation of this fact comes a sense of impending emptiness and loneliness and, what is more, a feeling that part of their own lives is about to be taken from them.

Lindemann (1963) outlines five major manifestations of normal acute grief reactions:

- (a) Somatic distress, such as sighing, weakness, fatigue and gastro-intestinal symptoms.
- (b) Pre-occupation with the image and memories of the deceased (or dying person).
- (c) Guilty self-blame in search of a cause.
- (d) Irritability, impatience and social withdrawal.
- (e) Inability to maintain normal patterns of conduct and functioning, with overactivity, restlessness and lack of initiative.

When the grieving occurs in an anticipatory process, the symptoms are not as dramatic or as condensed as they are in acute grief reactions. They are diluted over time and vary in intensity, according to individual patterns over the course of the child's illness (Wiener, 1971). Futterman, Hoffman & Sabshin (1972) suggest the sequential emergence of the following part processes of anticipatory grieving:

- (a) Acknowledgement: becoming progressively convinced that the child's death is inevitable.
- (b) Grieving: experiencing and expressing the emotional impact of the anticipated loss and the physical, psychological and interpersonal turmoil associated with it.
- (c) Reconciliation: developing perspectives on the child's expected death which preserve a sense of confidence in the worth of the child's life and in the worth of life in general.
- (d) Detachment: withdrawing emotional investment from the child as a growing being with a real future.
- (e) Memorialisation: developing a relatively fixed conscious mental representation of the dying child which will endure beyond his death.

One of the most important tasks for the parents involves maintaining investment in the welfare and future of the sick child, while also preparing for his death through anticipatory grieving. To love and retain emotional investment in the child, and to continue holding on to hope for his survival, is to become more vulnerable to the pain of his loss, precipita-

ting resentment and self-protective withdrawal. On the other hand, to disengage from the child and to begin to mourn before his death can be associated with killing the child, and can cause profound guilt. If family members experience active mourning and active caring as being incompatible, both processes may be blocked or distorted. Parents are also faced with the dilemma of maintaining a sense of mastery while simultaneously coming to terms with the terminal nature of the illness. They need to engage in meaningful caretaking operations while realising that, at the same point, despite their efforts, the child is virtually certain to die (Hoffman & Futterman, 1971).

As the process of anticipatory grieving continues, there is often a renewed interest in old family pastimes, in the other children, and in family affairs. The parents' hopes, like those of the child, become more limited and there are fewer questions about anything but the immediate future. Parents may now begin to spend increasing amounts of time with other children in the ward, even while their own child may be critically ill (Friedman, 1967). As a result, the family may isolate the patient psychologically and move him to the periphery of their family life, at a time when he most needs their support and love.

Buschman (1971) describes the dilemma with which the mother of a dying adolescent was confronted:

Rachel's blood gases and oxygen saturation level improved and she became noticeably more comfortable. Mrs H, at the news of Rachel's improvement, looked defeated. She said: "This is so difficult. Already I have said my farewell." Another mother who had been going through the process of anticipatory grieving said: "I love him as much, but we are more separate now."

Few family members understand the psychodynamics of what is happening to

them. They often feel guilty at the lack of emotion during the final phase of the illness and at the point of death. Mount (1980) stressed the fact that as a result of this, the bereaved represent a high risk population, and that serious psychological morbidity occurs amongst them.

In the first part of this chapter, the effect of the terminal illness and possible death of a child on the small nuclear family, in our modern, urban industrial society, has been discussed. The effects on the homeostasis of the family as a functioning unit, and possible attempts to cope with the loss and grief, were illuminated. The reactions of parents, siblings, the extended family, and significant others will be discussed in the remaining sections of this chapter.

5.2 THE PARENTS

According to Lederer and Jackson (1968), the major elements of a satisfactory marriage are respect and tolerance between spouses, and an effort from both to make the most of their assets and minimise their liabilities. Under normal circumstances, this is a difficult task and calls for devotion and hard work. In the presence of a terminally ill child, this task becomes more complicated and calls for sensitivity and courage. The impact of a young, dying child upon his parents is traumatic and includes such issues as the termination of parental hopes for immortality through the life of their offspring, guilt at perceived causal responsibility, feelings of failure as their nurturing efforts no longer result in positive growth and development, and simple despair at the loss of a loved person who may also be seen as an extension of themselves (Hoffmann, Becker & Gabriel, 1976). Terminal illness, in our time, means death following a

probably long, lingering and often painful illness. It frequently means revision of long-term goals for the child, and planning for the family planning on an almost day-to-day or week-by-week basis (Bouchard & Owens, 1972).

The threat which terminal illness of a child poses to a family has already been mentioned. Bozeman, quoted by Craig (1974), found that 87% of the families with leukemic children coped unsuccessfully with the many interpersonal conflicts superimposed on, or accelerated by, the stresses of the illness itself. Fields (1977) studied 39 families with dying children, and found that only 11 families had stable marriages. Along with the multitude of feelings of shock, denial, anger, guilt, anxiety, fear, despair and helplessness, which are typical of having to cope with a dying child, goes stress within the marital relationship itself, and intense frustration, possibly leading to a total breakdown in communication.

Of central importance is the nature of the marital relationship and whether the spouses are able to face the crisis together, each providing the other with support, comfort, strength, endurance, patience, tenderness and the positive sustaining activity necessary to keep their dying child as normal and happy for as long as possible, or whether the stress causes a further deterioration of an already existing weakness in the substance of the marriage. While it is true that, in some cases, a strained marital relationship may be strengthened by a shared response to such a stress, it is more likely that this will be only a temporary moratorium, as in an already strained, alienated, fragile marriage there will be less than adequate mutual support, each parent reacting and coping in isolation. One of the major causes of stress between parents may develop as a result of the two partners experiencing their grief at different times, expressing

their grief in different ways, and coping with their pain differently (Miles, 1984).

In many marriages, consideration for the children has been the overt reason for the parents remaining together. In such cases, both children and parents will have an undue degree of mixed feelings towards one another, and when a child in such a family develops a fatal illness, his parents may experience further discord in the marriage, inappropriate and non-supportive reactions towards the child, and feelings of guilt about such reactions (Wiener, 1971).

As mentioned previously, parents face the awesome task of maintaining a need-fulfilling task with a child whose expected death is being mourned during the period of hospitalisation. Some parents show remarkable capacity for this. Not infrequently, however, the illness sets in motion a regressive trend in the relationship, in which protectiveness fosters undue helplessness and dependency in the child. The parent-child relationship may assume a quasi-symbiotic nature and efforts of the staff to establish rapport may be resisted. This over-protectiveness may result from parents' separation anxiety, or the need to relieve guilt through atonement.

Parents quite often blame themselves for the child's illness and may go into excessive detail in trying to discover a place or situation where they may have missed cues, etc. Over-protection may also represent the defence of reaction-formation against unacceptable hostility towards a burdensome child who, through the illness, is ruling their lives (McCollum, 1974). Parents frequently comment on how "helpless" they feel, especially when they compare their own attempts to help with those of the skill of professionals (Anglim, 1974).

As a result of these inter- and ultra-psycho conflict during the lengthy period of terminal illness, the marital relationship may become non-existent and mother and child may become bound together in a symbiotic engulfment, from which the father is totally excluded. In such circumstances, all three people become isolated in terms of the wider world, incapable of accepting a place in the larger social group, and thus cut off from any help which the community could provide. Sometimes over-protective mothers may exclude others from their relationship with the child, thereby neglecting important aspects of home care and mothering of the other children in order to stay in close proximity to the dying child. Bührmann (1970) emphasises the destructiveness of such clinging and over-protective behaviour of the parents.

Some women feel they are in a sense "chosen", to carry the burden of having a dying child, because of their inner strength. Anger and resentment towards the dying child may be transferred at times to insupportive husbands. Other mothers defend themselves against feelings of despair by consciously suppressing the realities of the child's condition (Tropauer, Franz & Dilgard, et al, 1977).

Even where problems are not great, temporary marital stresses may arise from time to time, for example, when the condition of the terminally ill child deteriorates. The mother of a six year old cystic child said that at such times, when she hears the child coughing in the next room, she turns away from her husband in bed: "I'm so worried I can't be with it - and then I don't seem to be treating him right either". Divided loyalties and feelings of sexual tension and strain, all make for greater difficulty in coping with treatment and maintaining the necessary aura of optimism (Burton, 1974b).

Binger, Ablin, Feuerstein, Kushner, Zoger & Mikkelsen (1964) stresses the fact that fathers find many ways to absent themselves from painful involvement with their troubled families. They may escape to outside distractions, spending long hours at work, at the club, or participating in sports. They may then feel guilty about this and, as a result, use rationalisation as a defence. This type of behaviour often indicates the father's need for additional support. Although others may look upon such behaviour as expressing a lack of interest and concern, it is more often a way of avoiding the pain of ongoing involvement with his dying child. Wold and Townes (1969) suggest that fathers are often estranged from the care of their dying child through lack of knowledge of current treatment, added responsibilities at home resulting from the absence of the mother, and work stress because of the added financial burden resulting from expensive medical treatment. Fathers may also resent this continued and mounting drain on financial resources, becoming more and more bitter and increasingly unco-operative about the hospital bills for the dying child.

In addition, the clinical impression is that fathers are delayed in their mourning process and this delay, relative to the mother's mourning, may contribute to intramarital stress. Mrs L stated: "I don't think Ralph accepted it right up to the day Peter died." Another father related that the easiest way for him to cope with the problem was to seek no information about the child's condition, because knowing very little prevented him from thinking too much about the future.

Another problem with which parents are confronted is the prolongation of the life of their child, or rather the prolongation of the process of dying. Due to the rapid advances in medical science and technology, children can now be kept "alive" long after what used to be the final

crisis. The classical deathbed scene with its loving parting becomes a thing of the past in our modern hospitals where children are often placed in intensive care units, connected to life-supporting machines and, as a result, the process of dying is extended over hours or days. Complicating their anguish, parents are sometimes asked to make decisions regarding their child's clinical management, despite the fact that their knowledge of the disease or the clinical milieu is inadequate for such decisions. They may, for instance, be asked whether their dying child should be resuscitated in the case of cardiac arrest, or whether the team should proceed with active life-sustaining treatment when death becomes imminent. On being asked to make such choices, parents may understandably feel extremely helpless, angry and guilty (Fletcher, 1960; Glaser, 1970; Campbell, 1975).

5.3 THE SIBLINGS

Siblings form a child's first peer group. Within this context, children support each other, enjoy, attack, scapegoat and generally learn from each other. They learn how to make friends and deal with enemies, how to learn from others and how to achieve recognition (Minuchin & Fishman, 1982). Thus in order to understand a sibling's relationship with a dying child, one must consider difference in age, and sex, as well as the family constellation, the amount of time spent together, the parents' attitude towards all their children, and how open and honest they are able to be with their children (Fredlund, 1976).

The terminal illness and death of a sibling is an extremely profound crisis. Parents are often so caught up in their own reactions of shock and distress that they are unable to be supportive of their well children.

Their mental anguish clearly has an effect on the children, not always directly, but usually through the changes in the relationship with each other and in their behaviour towards the child. After a diagnosis of terminal illness has been made, the whole life of the family may revolve around the sick child. The attention his condition requires and the concern for his welfare may deprive the siblings of the care to which they have been accustomed, and which is essential for their development. Their interest, problems and joys may of necessity be relegated to a secondary place. The fact that mother suddenly spends most of her time at the hospital with the sick sibling and father stays at the office longer and later, may determine what they eat and when or whether they secure a restful night's sleep. They may be forced to give up a long-planned birthday party, or give up some of their extramural activities to tend to the needs of the younger children in the family. The reaction of siblings will depend upon their age, maturity, ability to comprehend and integrate the meaning of the illness, the particular relationship of the siblings with the ill child, the siblings' own place and adjustment within the family and, perhaps, most important, the honesty and appropriateness with which the parents communicate with them about the ill child and the nature of the problem. Much depends upon how they are included, as part of the family, in the adaptation to the crisis (Wiener, 1971).

Siblings may feel anxious, helpless and frustrated, witnessing a brother or sister suffer and being unable to help or to alleviate the pain. They may struggle with fears of contagion or inherited disease, or have fears about their own death. Close identification in death and in vulnerability may be felt. They realise that they too could become terminally ill and die, and that no-one (not even their parents) can protect them completely. Since the world is no longer experienced as safe, they may develop phobias and

undue fears. Nights are no longer tranquil and may be broken by nightmares and restless sleep. These children may know that they need protection and may be reluctant to move away from the protection of parents, family and teachers. As a result they may become more clinging and dependent, and may regress to earlier stages of thumbsucking and bedwetting. Because of the non-availability of support, they may become depressed, withdrawn and anti-social, in a desperate bid to attract attention and to win back their parents' love (Lamerton, 1973). They may be quick to notice disparities in discipline and handling between themselves and the sick child, and may feel jealous and resentful (Burton, 1975). They may feel shunted aside and angry towards their ill sibling. Initially, sacrifices may be made willingly and gladly by well children but, as the stress of such demands continue over a long period, the original concern for the welfare of the patient may be obscured and replaced by bitterness and resentment. Whereas in the beginning the well children, in identifying with the patients' suffering, resented the illness, later they may come to resent the sick child himself, as well as the sacrifices which his illness demands from them (Field, 1967).

The well children may resent their ill brother or sister and their parents, and may actually be glad about any bad news and even death. When five year old Stephan was told that his little brother had died, he exclaimed: "Goodie! Can I have Nicky's teddy and his bicycle? Will you now take me to Disney World and lots of shows, and play checkers, and can I have a story every night?" (Wass, 1982).

Binger, Ablin, Feuerstein, Kushner, Zoger & Mikkelsen (1969) found that in approximately half the families, one or more previously well siblings showed significant behavioural patterns which indicated difficulty in

coping. Problems described by parents included an onset of severe enuresis, headaches, poor school performance, school phobia, depression, severe separation anxiety, and persistent abdominal pains. They often experienced feelings of guilt and fears that they too might suffer a fatal illness. They misinterpreted their parents' preoccupation with the sick child as a reflection on themselves and, in their own way, experienced anticipatory grief reactions. Cain, Fast & Erikson (1964) found that children often manifested behaviour disturbances after a family death, and sometimes a child's personality was permanently altered.

In Chapter 2 it was suggested that young children's explanations for events in the physical world are animistic. They believe that everything is alive and that every event occurs by intent. They believe that they have magic powers and that their wishes, thoughts and words are the instruments of these magic powers. The psychological and physical world are one. Dreams rarely happen and good or bad wishes can quite possibly come true. Because they live in an egocentric world, everything bad which happens is likely to be seen as punishment for what they have done wrong (Wolff, 1973; Fraiberg, 1968). Therefore, because they are notorious "magical thinkers", they may assume that they are to blame for whatever is going on and have caused the illness and death of the sibling. In the young child, feelings of omnipotence may, in a sense, be confirmed by the disappearance of a brother or sister. His imagined power now frightens him and he may feel responsible for the sibling's fate. Such thoughts may be further strengthened by the subsequent apparent abandonment by his parents who are pre-occupied with their loss (Friedman, 1968). Some children still feel guilty many years after the death of their sibling. Much evidence has emerged from psychiatric work with child and adult patients regarding the destructive and permanently scarring effect of confused and unresolved mourning

experiences in childhood (Gordon, 1974). When they deal with the tragedy of a dying child, staff, relatives, neighbours, friends and teachers are usually very aware of the emotional needs of the dying child and the parents. Unfortunately, the siblings are generally largely ignored.

5.4 SIGNIFICANT OTHERS

5.4.1 Grandparents

The needs of grandparents during the period of terminal illness of a grandchild are rarely discussed, and little research has been done in this field (Miles, 1984). In their study, Binger, Ablin, Feuerstein, Kushner, Zoger & Mikkelsen (1969) found that grandparents sometimes represent a burden or hindrance during the course of the child's fatal illness. Gyulay (1978) quotes pediatric staff, and even parents, who said that grandparents are one of the biggest problems they have to cope with. This may be due partly to negative interactions which, to a considerable extent, reflect poor relations between parents and grandparents, and partly to grief reactions of the grandparents themselves. It may also be attributed to grandparents' lack of knowledge which, in turn, contributes to their ineffectiveness in helping the parents of the child. However, in all fairness, it needs to be stated that there are many families in which grandparents offer invaluable support and help.

Typically, grandparents tend to be less accepting of the diagnosis than the parents, often citing instances in which patients whose condition was considered terminal, rallied at the last minute and were eventually cured. They encourage the parents to take the child to well-known institutions,

or to a special physician, or to try a new drugs or therapy. They assiduously read and clip stories from periodicals describing instances of misdiagnosis or miracle cures. Their purpose may be to legitimise their own denial, or else to manipulate the parents so that they are not the only ones to decide on the care and treatment of the child (Gyulay, 1978).

Grandparents' grief is threefold as they grieve for their grandchild, their son or daughter, and themselves. Often they think they should cope better and be an example through the ordeal. They express guilt about not recognising the symptoms themselves, and anger that their child did not recognise them. Sometimes grandparents are not in good physical or emotional health themselves and are, therefore, unable to help their child with the physical care and emotional strain of the illness of their grandchild. Behavioural disturbances such as disorganisation, disorientation, and poor decision-making, may already be problems if the grandparents are elderly, and these symptoms may become exaggerated during grief, and therefore profoundly difficult to cope with (Miles, 1984). They may feel intense failure as parents, and also as grandparents. Instead of helping, they may find themselves accepting support from others. Conversely, some grandparents feel lonely and angry because no-one seems to recognise their pain (Hamilton, 1978). Parents may feel that the grandparents ask for emotional support at a time when it is most difficult for them to assume this supportive role (Friedman, Chodoff, Mason & Hamburg, 1963).

Grandparents may experience particular difficulty in sharing and facing their pain, because of the masculine stereotyping of their generation, in which men were not supposed to cry or share feelings. Nevertheless, they may experience all the previously mentioned symptoms of grief (Miles, 1984). They may feel frustrated, helpless and angry, with their anger

being directed towards their child or grandchild, or at staff who do not appreciate all they do. Their anger may also be a projection of their own guilt which they often attempt to resolve by conducting an intensive, though futile, search for the cause of the illness. They may also become over-protective of their child and grandchild to the extent that they may forbid open discussion and/or any punishment. When siblings want to talk about illness and death, they may be scolded for being insensitive and bad. Some grandparents go a step further and warn siblings not to worry their parents with any questions.

Grandparents who have been through the experience of loving a child themselves may indeed need more support since they know the pain that their own child is going to face. Although they can empathise, they are often unable to give advice for fear of scaring the parents about all that lies ahead.

5.4.2 The Child's Peers and Friends

In addition to the family and its cultural background, the dying child is part of the cultural setting provided by school and peers. The school represents the workplace for the child, complete with achievements, failures, discipline, socialisation and, most importantly, a sense of belonging. For the dying child there is a need to be part of the class, to maintain contact with the teacher, and to keep active for as long as possible. Peers at school, in the neighbourhood, and in other settings, fulfil the child's need to be part of a group, to be recognised and to be regarded as being just like other children.

It is, however, important to recognise that peers and friends are children too. Like siblings of the dying child, they also have fears and fantasies about death and dying. They feel anxiety and guilt, often exacerbated by the school setting and their own home situation, where death is often treated as taboo, and where adults and teachers may pretend that the dying friend or student does not exist. Unsupported and alone, they find it increasingly difficult to remain close to their friend who is dying and desperately reaching out and holding on to them. They find it impossible to share their goals, their achievements, their activities in and out of school, with a child who is dying and who asks to stay in touch with the outside world and his friends, until the end (Gyulay, 1978; Adams, 1984; Coleman & Coleman, 1984).

5.5 CONCLUDING REMARKS

The terminal illness and death of a child and sibling is a traumatic experience for every member of the family.

Each person in the house, however young or old, has to adjust to the numerous changes in him- or herself, and in the home, brought about by the illness and eventual death of a sick child. They have to cope with intensive feelings of loss and grief, and a number of other feelings which, up to that stage, have never been experienced. At the same time, they have to retain their identity and keep functioning as an individual, a couple, a family, and members of the community. Furthermore, every effort must be made to keep the family system from disintegrating.

All this has to happen in a world which will never change pace to

accommodate individuals or families, but instead continues to expect sufficiency and performance, without providing support and caring. As a result, marriages may end in separation and/or divorce, and individual members of the family may carry with them the scars of the unresolved emotional turmoil, so frequently a part of this traumatic experience, for many years to come. The results of research conducted in this area are alarming, showing that the terminal illness and death of a child is certainly a devastating experience in the life of a family. Emotions experienced are intense and comprehensive. At times, shock, anger, guilt, depression, sadness and grief can be identified and at other times they are intermingled and confusing, to the point where they become threatening and overwhelming.

Although the nuclear family functions as a self-contained unit, almost in isolation, the terminal illness and death of a child also affect grandparents and other family members. It also ripples through a community, affecting peers and friends. Unfortunately, because of the almost universal denial of death and feverish investment in life, the emotional needs of those affected by the death of a child are hardly ever recognised, let alone harnessed.

CHAPTER 6

CARING FOR THE FAMILY

6.1 INTRODUCTION

While advances have been made in the medical and surgical treatment of children with malignant diseases, the family of the child with a life-shortening illness faces massive and multi-faceted challenges and stresses, caused by ongoing treatment and the eventual death of the child. Chapters 3 and 4 dealt with the needs of the dying child, and explored various ways in which these needs could be met. However, the dying child cannot be helped in any really meaningful way if the family is not included. The family then, which includes the dying child, is the basic unit of care.

As has been illustrated in the previous chapter, significant alterations in family life-style may become necessary during the terminal illness of a child. For example, the family may have to move closer to available medical facilities, parents may be required to change jobs, recreational activities may be curtailed because available time and funds are limited and educational or vocational plans for siblings may be compromised because financial resources become depleted. The fact of the matter is that parents do not have much control over the unique drama which begins to unfold in their lives and this may lead to moments of difficulty or even despair (Carlson, Simacek, Henry & Martinson, 1984; McCollum, 1974; Parkes, 1978).

Because of this broad spectrum of alterations, stresses and needs, the family of the terminally ill child is at risk. Parental reactions to an acute life-threatening illness in a child may have long-term psychologically deleterious effects on both parents and children (Green & Solnit, 1964). Sanders (1979) compared the intensity of bereavement across types of bereavement suffered by parents, and concluded that the death of a child produced the highest intensity of bereavement, as well as the widest range

of reactions. Higher death anxiety in parents resulted, in part, from feelings of loss of control over their life and the world. Most of the parents appeared to have suffered a physical blow which left them with no strength to fight, hence they were vulnerable and in despair.

These findings support Gorer's (1965) conclusion that the death of a child is the most difficult and longest lasting grief to bear. On the other hand, the maintenance of their role as parents throughout the crisis of their child's dying seems to make resolution after death more possible.

Thus, the illness and death of a child may either result in ever-widening circles of social and psychological pathology or, with appropriate help, it may stimulate the family to develop effective coping behaviour and emotional bonds of enduring strength by remaining sensitive to potential sources of stress, some of which have been discussed in the previous chapter. The clinical psychologist can help parents maintain or re-establish constructive communication of needs, attitudes, worries and feelings among family members. In so doing, the psychologist may make a preventative, as well as therapeutic, contribution to the family's mastery of the challenge of the terminal illness of a child (McCollum, 1974). The purpose of this chapter is to stimulate consideration of possible methods of intervention and to provide guidelines for ways in which the family can be assisted during this very traumatic time of their lives.

6.2 ASSESSMENT

In dealing with fatal illness and dying, families seldom perceive themselves as being in trouble, and seldom actively seek help. Even when

help is volunteered, they may well feel suspicious and mistrustful, and may at first reject offers of assistance (Krant, 1974b). As previously stated, the clinical psychologist, being a committed member of the treatment team, has the responsibility to make immediate contact with the dying child and his family, from the very first point at which they are seen by the medical team, which contact will be continued until after the death of the child. In this way, the family can relate to the psychologist on a regular basis and, consequently, not be forced to label themselves as having "emotional problems" before seeking assistance. From the outset, such intervention should be aimed at restoring the stability of the family group, enabling it to cope more adequately with the present crisis and with the crisis of bereavement to come, thus enabling it to return, ultimately, to a healthy rather than a pathological equilibrium.

Until the clinical psychologist fully understands the implications of the illness and possible death of the child for each individual member of the family as well as for the child, the effects which the illness has on each person, on the marriage, and on the family system, he will not be able to help the family members to adjust and care for the dying child.

Each member of the family reacts to the tragedy of terminal illness in a unique manner, consistent with his or her particular personality structure, past experiences and the individualised meaning and specific circumstances associated with the threatened loss (Friedman, Chodoff, Mason & Hamburg, 1963). For the above reasons, a full assessment of the family is important before any therapeutic intervention is undertaken. The necessary information may be obtained through a thorough psychiatric history and careful observations of each family member's response to the crisis.

6.2.1 The Individual Family Member

The needs of the individual member, as already emphasised, can only be understood in the light of knowledge of his own developmental background, the particular roles which may be pathogenic for him, the particular conflicts which are being mobilised, and the defences which he is using. An unendurable reality, such as the terminal illness of the child, can only be assimilated in manageable proportions over a period of time. Therefore, family members must be expected to ward off this threat by employing a variety of psychic defences such as denial, repression and isolation of affect. Such defences serve a necessary role in protecting family members from incapacitating despair, depression and anxiety. A careful appraisal, by the skilled psychologist of the individual's defences can help to ensure that his needs are adequately met. The psychologist also needs to assess the extent to which the impending death of the child constitutes a crisis situation for family members (Maddison & Raphael, 1972). People in acute stress, such as the terminal illness of a child, tend to bring to the fore earlier traumata or failures so that in helping family members to work through the immediate ordeal, it is often possible to help with unresolved aspects of earlier events (Gordon, 1974) as well.

6.2.2 The Family Group

During the crucial days and weeks of a child's terminal illness much depends on the structure and unity of a given family - on their ability to communicate, and on the availability of meaningful friends (Kübler-Ross, 1969). Understanding the problems of the family group itself is only possible if there is an understanding of the imposed changes in role behaviour, the extent to which resources are being concentrated on the ill

child, the significance of family concepts of the sick role and death, past and present communication patterns within the family, the extent to which denial is employed, attitudes towards hospitalisation and care at home, the presence or absence of support from the extended family and, finally, the extent to which the situation is perceived as a crisis by the family itself (Maddison & Raphael, 1972). Furthermore, because family systems differ in their ability to cope constructively with the stresses and strains imposed by terminal illness (Vollman, Ganzert, Picher & Williams, 1971), adjusting to this illness involves a shifting of tasks, roles, affection, discipline and resources (Lindsay & MacCarthy, 1974).

The competent psychologist, in assessing the family, will evaluate the different sub-systems individually, the boundaries between systems and the transactional patterns, and will determine whether there is pathology in any of these aspects of the family (Minuchin, 1974; Munson, 1978). The psychologist should also assess the important landmarks in the history of the family and problems which they have had to face. His knowledge of previous patterns of family behaviour in times of stress can aid him in encouraging family members along lines which have been successful in the past, and in supporting attempts to adapt to the current situation.

It may be useful to examine some of the mechanisms which families use to maintain a relatively acceptable level of functioning. Binger (1969) found that personal religion and religious concepts seemed to be of considerable help to families in coping with terminal illness of a child. However, Oates (1970) warns about the danger of sick religion, and the psychologist needs to be aware of this. Sick religion refers to specific situations in which particular people suffer major failures of functioning in the conduct of their lives because of religious pre-occupations and stumbling blocks.

In other words, when the word "sick" is used, it is employed in a restricted, rather than a general, sense. As mentioned above, the adaptive mechanisms or coping behaviour used by the family may include defences such as denial and projection, but also any emotional expression, motor activity or social behaviour which helps the individual to deal with the stress (Friedman, 1968). In summary, knowledge of the total family configuration, the functional position of the dying person in the family, and the overall level of life adaptation, are important for the clinical psychologist.

6.2.3 The Marital Relationship

The marital relationship is subject to severe strain. There may be bitter recriminations concerning the cause of the illness and differences between spouses' coping behaviour may result in alienation between them. One parent may seek comfort in closeness, wishing to share her grief in words and tears, while the other, in contrast, may deal with his grief by withdrawing emotionally or physically. Aloof and inarticulate, this parent leaves his partner feeling abandoned and alone. One parent may be excluded from a meaningful role in the child's care, and thus be subject to intensification of his feelings of helplessness and guilt, or the father may deliberately find ways to absent himself from painful involvement with his troubled family. The sexual relationship may be disrupted by fatigue, fear of another pregnancy, or diminished time for intimate togetherness.

A central consideration then, for the clinical psychologist, is the marital relationship. He has to determine whether the parents are facing the crisis together, each providing the other with support, comfort and strength, or whether the stress is exacerbating already existing weaknesses in the substance of the marriage (Wiener, 1971; McCollum, 1974).

6.2.4 Parental Functioning

Dying children and siblings may become hostile, particularly towards their parents. The manner in which parents support each other in response to the child or children's abusive behaviour requires attention. The psychologist must be aware that the combination of the stress of the anticipated loss and the children's anger may overwhelm the parenting system. A mother may chastise her husband openly in front of the children for being too strict. Similarly, the husband may be critical of his wife for being too protective and permissive with the ill child, thus undermining the parental roles (Munson, 1978).

Another possibility is that siblings may be selected to become the focus of the parents' anger and may be expected to "make up" for the dead child in the years to come, thus contributing to feelings of helplessness and low self-esteem in the surviving sibling. Parents may also become over-protective with the surviving sibling, never allowing him to become independent.

Besides causing difficulties with siblings at home, rigidity in the parent sub-system can lead to many problems for parents of a dying child. Such children, when ill, often regress to behavioural patterns which are immature and dependent. Such regression, although encouraged by the illness and the hospitalisation, may be difficult for rigid parents to accept. The clinical psychologist should be alert to the needs of both the dying child and his parents. Children who are not used to other caregivers may find the parents' sudden absence traumatic, and may react with anger and rejection towards any substitute parent. A thoughtful question by the

psychologist about how the children are getting along with the temporary caregiver may lead to detection of a potential problem (Munson, 1978).

In summary then, it is clear that a proper evaluation will benefit not only the dying child, the parents, the siblings, and the extended family, but may also serve to safeguard relationships between parents and hospital staff. The clinical psychologist's understanding of the psychodynamics of verbal and non-verbal behaviour puts him in an excellent position to explain behaviour, and so defuse tension which could easily develop at the bedside of a dying child. An evaluation and understanding of defences used will enable the clinical psychologist to reassure parents about the appropriateness of their defences. Furthermore, proper assessment may indicate which family members are at special risk and may experience an emotional breakdown before or after the death of a child. Parkes (1978) found the following people to be at special risk:

- (a) Persons of low socio-economic status.
- (b) Houswives without employment outside the home.
- (c) Those with young children at home who may themselves be at risk.
- (d) Those without a supportive family, or with a family who actively discourages the expression of grief.
- (e) Those who show a strong tendency to cling to the dying child before his death and/or to pine intensely for him afterwards.
- (f) Those who express strong feelings of anger or bitterness before or after the child's death.
- (g) Those who express strong feelings of self-reproach.

6.2.5 The Siblings

At the time of the terminal illness of one of the children, the parents may be too involved in their own sadness and despair to heed the siblings' own needs. They may become less attentive to the children and to accustomed secure routines. Thus, these children are confronted with the need to cope, not only with the loss of the sibling who is in hospital and dying, but also with the changed behaviour of their parents, with resultant increased anxiety, tension and feelings of insecurity and instability.

A proper evaluation of each sibling and of the sibling sub-system is essential. Gathering objective information about this is difficult because direct observation of each sibling's behaviour is not always possible. Answers to specific questions about the siblings at home should be gained on a regular basis from both parents. The psychologist may try to make contact during their visit to their sick sibling, or he may do a home visit, to establish the necessary contact. Information should be obtained regarding schoolwork, appetite, sleep patterns, discipline, peer relationships, general mood, as well as what they understand and what questions they may be asking about the sibling's illness (Munson, 1978; Rudolph, 1978).

6.3 THERAPEUTIC INTERVENTION WITH THE FAMILY

A family system is in functional equilibrium and each member functions with reasonable efficiency in periods of calm. This equilibrium is severely disturbed by the terminal illness and threatened loss of one of its members, and by absence of other members from the system.

The primary disruptions for the family of the terminally ill child are the separation, forced by hospitalisation of the child; the stresses attendant upon hospitalisation, including feelings of loss of control; and the additional financial expenses encountered by the family. Separation of family members has been viewed as a threat to family integrity (Carlson, Simacek, Henry & Martinson, 1984) as family activities are terminated or curtailed when one or both parents are at the hospital with the dying child and the siblings remain at home. To prevent the weakening of the family unit, parental participation in the care of their dying child has been advocated as a measure to increase involvement, but this may result in unavailability at home with the siblings. The intensity of resultant emotional reaction is determined by the emotional integration in the family at the time, and by the functional importance of the dying child. To help families in this situation, the clinical psychologist may find it effective to begin with the current state of disequilibrium through interviews with varying combinations of individuals, family sub-groups, or the total family as a group, and work towards unlocking forces in the form of new knowledge and energy for improved adaptive functioning.

This section will consider how the psychologist may intervene with the family as a whole, and with each sub-system.

6.3.1 The Family System

At the first level of intervention, the psychologist may work with the family as a whole. Important areas to be investigated include the roles, communication patterns and the ways in which the family, as a system, reacts to stress.

6.3.1.1 Roles

The psychologist must help family members to understand roles and role relationships in the family, and the subsequent disruption caused by the terminal illness of the child. They must be helped to negotiate the altering of relationships or the ways in which roles will be filled, so that responsibility and needs may be redistributed. Redistribution occurs with regard to instrumental and socio-emotional factors. If agreement cannot be reached, roles are left unfilled or may unnecessarily overlap, which could lead to possible conflict.

The potential for disagreement and conflict increases for the family which is more advanced in its life cycle because, in these families, children have a greater voice by virtue of being older and by virtue of being future or present income producers who can be tapped for support. There may be several reasons for conflict: continuation of conflict regarding role definition prior to the death of the child, several persons able or willing to assume the same role, and lack of clarity as to what the role entails.

Another possibility may be that the dying child previously fulfilled a socio-emotional role in the family which kept hostilities and conflict dormant, or at least under control. With the removal of the child through illness, what was latent now becomes active. The child may have served to bind the parents in a tenuous relationship and his absence from the family system may lead to the surfacing of difficulties previously held in check. If the dying child played the role of scapegoat in the family, readjustment during hospitalisation must take this into account. The psychologist with a realistic knowledge of family dynamics will regard as a priority the readjustment of family structures and role network. The

family may begin to reassign role responsibilities, both instrumental and expressive. The nature of these responsibilities, and the abilities of specific members to carry them, must be clarified with the help of the psychologist. If roles cannot be realigned, the threat of collapse occurs. The psychologist will help the family in dealing with these conflicts at a time when feelings of abandonment, anger and hurt are prominent and added burdens pose threats and tend to create emotional overload or stress, especially when compounded with relational conflicts and dysfunctional communication at a system level. For the individual, anger, fear, or guilt may be a crippling dynamic (Orcutt, 1977).

The literature on family crisis theory delineates three variables which characterise families who are better able to cope with crisis events, namely, involvement, integration and adaptation (Glasser & Glasser, 1970). Because the family members are involved with each other, open to new input and willing to integrate differences and changes, the family group and each of its members are able to adapt and to change their responses to one another and the world around them, as the situation demands. Thus, flexibility of the family in group structure and flexibility of individual family members facilitates coping in crisis situations and role reorganisation is initiated (Goldberg, 1977).

6.3.1.2 Communication Patterns

Communication amongst family members becomes a complicated matter because it not only involves speaking, listening and really hearing, but it also involves emotions. Communication is a sadly neglected art in many families (Kohn & Kohn, 1978) and, given the intensity of emotional reactions when the terminal illness and anticipated death of a child are involved, many

family members are helpless in dealing with each other's emotional needs. The degree to which it is permissible to express feelings of sadness and loss, as well as the less acceptable reactions of anger, guilt and relief, seem to play a large role in determining the success of the period of reorganisation and adjustment (Vollman, Ganzert, Picher & Williams, 1971).

In order to open a closed communication system in a family, Bowen (1976) suggests that direct words be used by the psychologist, such as cancer, death, die, bury, anger and sadness. The use of less direct words such as growth or cyst, passed on, deceased, expired and emotional upset, must be avoided. Direct words signal to the family that the psychologist is comfortable with the subject, and this also enables the family to be comfortable with the material in each other's presence, however painful it may be. Tangential words may appear to soften the fact of death, but they invite the family to respond with tangential words, and conversation soon reaches the point of superficiality, with the result that communication is closed off. Barriers to communication tend to grow out of a need to protect family members from hurt or sadness or accumulated feelings of bitterness. Bowen (1971) observes that a slight improvement in communication can produce dramatic shifts in the feelings and relationships of family members. Open communication about the reality of the forthcoming death is a goal the psychologist can hope to achieve.

6.3.1.3 Reaction to Stress

Stress theory implies that the family system has been thrown off its customary equilibrium and that relationships between family members show evidence of strain. Thus, the psychologist's goals for a family with a

adaptive functioning of the family in view of this reality. Support may be directed towards encouraging more sharing and understanding, towards improving the quality of communication, as stated above, and towards flexibility in the family rule patterns. He may attempt to arouse awareness and sympathy with regard to relational conflicts, thus reducing alienation between the dying child and the family, by dealing with the pain and grief of feelings stirred up around the impending loss and abandonment. In this way, the psychologist can initiate the process of anticipatory grieving in the family. The processes of grief, anger, remembering, longing and identification, can be worked with in preparation for the final separation and decathexis of the patient - which is of crucial importance (Furman, 1974). Providing a setting which nurtures empathy is indeed one of the invaluable benefits of family therapy, for it allows every person in the family to feel he is not alone.

The psychologist will be aware that anger and hurt may be displaced onto other members of the family, and he will attempt to help the family members develop more constructive need-response patterns (Arndt & Gruber, 1977; Goldberg, 1977; Benoliel, 1981).

In conjoint family therapy sessions, where one spouse exhibits maladaptive responses due to the terminal illness and anticipated loss of the child with deposits of anger, grief, guilt, bitterness, regret and so forth, and sees his partner as not understanding, rejecting and uncaring, the psychologist must be careful not to focus exclusively on the anticipated loss, but must encourage family members' recollection and expression of feeling around difficult life experiences which relate to the family's current distress. The listening members tend to be effectively moved as they become aware of the meaning of the pain of these experiences and how

they relate to the current behaviour. With this awareness, empathy and warm affection tend to flow, and the relationship begins to take on a different meaning. The spouse who has seen his partner as rejecting and uncaring can link these reactions to an earlier hurt or bitter experience, rather than interpret them as directed solely at himself. He also achieves some awareness of how his own behaviour can set off these reactions to the earlier hurt. Actually, the family or the marital dyad is now in a position to perceive the reality more correctly and with empathy. This procedure, which Orcutt (1977) calls "relational awareness with empathy", can be used effectively by the psychologist, particularly when conflict or bitterness is present.

Grosser and Paul (1971) generalise goals for conjoint family therapy which are pertinent to the psychologist's intervention with the family of a dying child. Their goals, as modified by Orcutt (1977), are as follows:

- (a) to accept the existence of illness, deviance, and differences as they exist and affect the family;
- (b) to broaden family capacity for reality testing and consensual validation as a check on projections and distortions, by encouraging family members to review the same event from their respective points of view;
- (c) to encourage family members to share feelings and concerns with each other as emotional release and elimination of barriers in relationships;
- (d) to encourage each family member to develop a greater capacity for

empathy and for observing ego functioning in tolerating anxiety;

- (e) to increase tolerance of frustration when confronting disappointment, loss and new burdens;
- (f) to assist in providing for mutual accommodation and adjustment of role relationships in accordance with newly perceived appreciation of reciprocal needs, perceptions, and feelings, and
- (g) to foster environmental supports for social roles and material needs.

The psychologist must also:

- (a) be aware of, and sensitive to, the importance of non-verbal communication;
- (b) assure every family member that the exposed feelings, whatever they may be, are normal and natural;
- (c) be alert to a variety of psychological and psychosomatic reactions which usually emerge - anxiety states, depression, mood swings, gastrointestinal disorders which simulate organic disturbance, etc., and
- (d) slowly prepare the family for the loss of him as their therapist. Their completion of mourning for the loss of a child and sibling will enable them to cope more adequately with new losses, including

the loss of their psychologist on whose catalytic presence they may have become dependent.

In summary, it is clear that the terminal illness and death of a child is a shattering and highly disruptive experience for individual members of the family, and for the family system as such. To establish a new emotional equilibrium and integrate the traumatic experience emotionally, the family needs the sustained help of a competent clinical psychologist who is able to recognise the burden which they are called upon to carry. He needs to provide the space and create an opportunity for family members to voice their pain and anger; their sadness, frustration and grievances. Through involvement in conjoint family therapy, they will be given the opportunity to participate actively in the therapeutic process which may enable them to develop a new awareness of themselves as individuals and as a family, to care for and love their child until death finally separates them.

6.4 THERAPEUTIC INTERVENTION WITH THE PARENTS

6.4.1 Introduction

The disclosure to parents that their child has a terminal disease triggers a series of intense emotional reactions which may influence their lives and the lives of people around them in a profound way. The physician, who is in charge of the co-ordination of their child's care, will be responsible for giving them complete and consistent information about their child's illness and prognosis. However, in modern hospitals, the danger exists that the physician may leave without communicating either the content of his announcement or his therapeutic plans to the staff, who are left to

deal with questions which they feel ill-equipped to handle (Hoffman, Becker & Gabriel, 1976). The clinical psychologist must therefore insist on a problem-solving conference, where information can be shared and strategies can be devised, either before or after the physician sees the parents. The clinical psychologist will interview the parents as soon as possible, to help them to recognise and express their feelings.

Parents may require assistance in overcoming their deeply rooted aversion to showing emotions. From early childhood, they may have been taught to mask their feelings and may have been praised for suppressing emotional reactions to falls and injuries, being told that it was good to be brave, and bad to show weakness and helplessness. The psychologist may need to make them aware of the therapeutic value of "a good cry", by which is meant full, uninhibited weeping. He can achieve this by listening empathetically and providing them with the space and privacy they need at this stage (Gordon, 1974). Being knowledgeable about the situation, the psychologist will be able to help the parents to have neither unrealistic hopes nor irrational fears.

6.4.2 Coping with Feelings

Parents have a difficult, two-fold task as they struggle to maintain their equilibrium. They need to love and care for their sick child, yet, at the same time, they must deal with intense feelings as they anticipate the inevitable loss in the future (Wessel, 1984).

6.4.2.1 Shock

In spite of the fact that they may have suspected the critical nature of the disease, parents are stunned at hearing the news and having their fears confirmed. It is important for the psychologist to remember that, given the diagnosis of terminal illness, parents can only truly understand what they are ready for, owing to varying degrees of anxiety. Thus, the psychologist must provide the opportunity for them to work through a continual questioning of medical information, its implications and impact, and move towards gradual acceptance.

The management of grief during the shock phase is primarily non-verbal and supportive. The psychologist must make himself available to the parents throughout the acute stage, as a strong figure who is a competent member of the team, working in close contact with the physician and other members of the team, and who can sustain them throughout their psychological crisis. During this time, he should attempt to avert any possible hysterical reaction in an emotionally labile spouse. Where necessary, intervention must be prompt and firm. Active intervention in excessive loss of control is important, because emotional outbursts may progress in severity and spread by contagion to others in the environment. Assuming that no possibility of hysteria threatens the situation, the psychologist can allow the parents to give way to their emotions and offer them verbal and non-verbal support. Physical contact at this stage is of basic importance, and far more important than words (Verwoerd, 1966).

During the period of shock, the psychologist may find it useful to warn parents not to hurry to tell others of the tragedy. Until they have had a chance to begin to assimilate the news along with its meaning and demands, it is better to tell as few people as possible. When parents do seek

solace by immediately informing family and friends, the result is usually counter-productive because they are not yet able to respond to the multitude of questions, to the outpouring of sympathy, or to the flood of medical advice. It is better for parents to first have some idea of how they feel and what they are going to do, before they face the additional problem of explaining the situation to others (Schowalter, 1978).

Sometimes parents can be encouraged to live one day at a time, seeking to achieve immediate goals. To live in the present can keep tensions at manageable levels, but it is difficult to simultaneously prepare for the uncertain future (Arndt & Gruber, 1977).

6.4.2.2 Anger

The massive threat and frustration and consequent aggressive impulses and anger which the child's illness arouses in most parents may alienate them from significant sources of help and support. The psychologist must appreciate that the parents' anger may be merely an expression of the anger inherent in any normal and natural process of mourning. However, he must take great care not to respond to outwardly illogical anger in an irrational fashion by reacting to an attack with a counter attack. At the same time, he need not tolerate unrealistic and unproductive anger, but should rather assist the parents in channelling their anger in a productive fashion. Such channels include ongoing group or individual therapy, joining support groups, joining an organisation to raise funds for medical research, or by joining societies which work towards prevention or earlier detection of cancer. The anger of the mourning process can be directed so that it leads to prevention and cure for others.

It can also have preventive as well as therapeutic importance if the psychologist can help the parent contain his anger by exploring and ventilating it within the therapy sessions, and by finding appropriate channels for discharge outside. Housecleaning and gardening afford numerous opportunities for aggressive movements, such as scouring, scrubbing, kneading, pounding and shoving. Many sports require physical attack, such as hurling, walloping and kicking, while others engage the body in rhythmical, repetitive movements which are tranquillising.

However, if the parents become so attacking that they tend to disrupt the treatment process, it may be most helpful if the psychologist explains to them why they are reacting in this fashion (Easson, 1970; Easson, 1977; McCollum, 1974; Wass, 1982).

6.4.2.3 Guilt

Verwoerdt (1966) states that the continued existence of guilt in family members complicates the successful resolution of their grief by prolonging the period of bereavement after the patient's death to such an extent that a rather serious depression may result from their inability to disentangle themselves emotionally. In order to communicate effectively and reduce some of the stress which the parents experience, it is necessary for the psychologist to recognise their guilt, reviewing with the parents their fantasies of omission or commission. Appropriate information can be sought from the physician, to help dispel such fantasies and with guidance and support from the psychologist, the parents can be assisted in clarifying the objective reality. The psychologist's understanding and acceptance support the parents in acknowledging and verbalising troublesome ideas and impulses.

Guilt feelings may be appropriate or neurotic (Clinebell, 1966). Where guilt feelings are appropriate and there are strong religious connotations, the psychologist may be wise to refer the patient to a competent chaplain to deal with these feelings. Often all the psychologist can do is point out that facts, however terrible, must be accepted although their obligations as parents do not stop. The husband must continue supporting his wife, and vice versa, and both of them are needed by the siblings.

Parents need to be assured, before they ask, that the illness was not caused by anything they did or did not do, and that they did not cause any harm in delaying seeking medical care. Parents can also be helped to recognise that all parents have some negative feelings towards their dying child; that these are often appropriate responses to the child's behaviour and that parental disapproval plays a necessary role in child rearing. These feelings can be dealt with effectively in a group situation (McCollum, 1974; Toch, 1972; Arndt & Gruber, 1977; Friedman, Chodoff, Mason & Hamburg, 1963; Verwoerd, 1966).

6.4.2.4 Anxiety

Anxiety may be generated by the intensity of grief reaction, and parents often have fantasies of being engulfed by their emotions, losing control over such behaviour, and losing their capacity for continuing functioning under such stress. Such apprehension and anxiety can often be ameliorated if the psychologist allows parents the opportunity to explore and verbalise their fears. Clarification of these fears subjects them to reality testing. Parents can be helped to recognise what information is needed to enable them to distinguish fact from fantasy. The sense that their fears

are understood is supportive. Furthermore, direct reassurance can be offered that certain thoughts and emotions are prevalent amongst grieving parents, and that they are not unnatural or indications of going "crazy". In certain cases, parents will benefit by the use of relaxation techniques (Wolpe, 1973). Direct and active involvement in the dying child's care may also not only alleviate anger but also anxiety (McCollum, 1974; Wass, 1982).

6.4.2.5 Denial

Although the development of open patterns of communication is indicated, a forced openness too soon can be destructive for some parents. There are parents who demonstrate a marked ability to function under stress, and others who exhibit maladaptive behaviour, becoming inaccessible, withdrawn and remote. The psychologist may help parents to become gradually aware of the false sense of equilibrium which they may derive from excessive denial of the situation, and the harm such denial can cause the dying child. However, especially in the beginning, if a temporary use of denial proves helpful in allowing the parents time to find adaptive resources, then such short-lived denial can be useful in the overall adaptive effort.

When the child goes into a remission and is sent home from the hospital, some parents equate this discharge with cure and deny that terminal illness was diagnosed at all. The psychologist must discuss in detail with the parents the realities and purposes of any visits home, or any decision to discharge the child from hospital. He must help the family not to have unrealistic hopes, nor to have irrational fears (Easson, 1970; Spinetta, 1978).

6.4.2.6 Anticipatory Grieving

The clinical psychologist must understand the dynamics of grief (Lindeman, 1963) in order to assist parents. At times, it may be necessary for him to explain the process and interpret the parents behaviour to them. While individual reactions will vary, usually they feel the pain of anticipated loss, anger, guilt and fear. The pain and fear arising from the impending death of the child are eased as they are helped in therapy sessions to express their feelings. Some parents may be hesitant to share deep feelings, especially those of anger and fear. The psychologist can gently encourage them to experience and express their feelings, using universalisation and partialisation, as indicated. As the psychologist responds empathetically, both verbally and non-verbally, parents are provided with a model through which they can give mutual support in sharing their reactions.

In cases of prolonged illness with several relapses and remissions, parents gradually disengage themselves emotionally and physically from the child, because they have mourned the child and said goodbye. Such children may find themselves isolated and alone. The psychologist should therefore not allow the emotional patterns of grieving to become too fixated. He must check on how often the child is being visited and must take care that parents do not use visiting regulations as an excuse to stay away from their dying child. He must also be aware that parents may prompt him into saying something that would justify their staying away. For example, they might wonder if their visits tire the child and, if the psychologist agrees, might use this as a rationalisation for not coming to see the dying child. The psychologist must encourage meaningful involvement in the total treatment of the child and the parents and child must continue interacting

with each other, even in a minimal fashion, so that the separation inherent in death is worked through in a fashion which allows continued family growth (Easson, 1970; Fulton & Fulton, 1972; Gibbons, 1974; Arndt & Gruber, 1977; Barckley, 1968).

The Lazarus syndrome is relatively rare, but may cause treatment complications when it does occur. This syndrome occurs on those occasions when a child is diagnosed correctly as having a terminal disease and, after the parents have already mourned his approaching death, the child recovers unexpectedly or has an extended remission. In this kind of situation the parents and child are faced with a very difficult emotional task. If the child has been mourned realistically, he will find that his family has left him and he has left it emotionally. If the child recovers from what should have been a fatal illness, he has to move back into his family as a new member, and his parents and siblings have the difficult emotional task of adapting to this new and unexpected return.

The psychologist and the family must face this unexpected situation very realistically. Not only must the psychologist help parents to verbalise their feelings, which may be very ambivalent, but he also has to explain the psychodynamics of these feelings to them. Furthermore, he can help the parents to accept and learn to love this stranger, who happens to be their child (Easson, 1970).

6.4.2.7 Intervention through Groups

The psychologist can use the therapeutic impact and the healing power of a small group to assist parents during and after the terminal illness of their child. The group provides a setting for sharing any and all

experiences and feelings. Support of the group comes from knowing that all the members of the group are undergoing a similar profound emotional experience and, to some degree, understand each other's feelings. The value of the small group experience can be summarised as follows:

- (a) The small group atmosphere allows for open communication among the parents with regard to their own personal problems relating to their particular situation.
- (b) The basic need to feel that one is not alone in this situation can be met by informal sharing and mutual caring.
- (c) Because the group is small, it is possible for the psychologist, as leader, to focus on individual problems and situations.
- (d) Informational materials on malignant diseases, provided to all parents, can aid them in facing the various stages of their children's conditions.

The psychologist can encourage parents to become involved in the care and planning of the child's treatment. Mothers are usually better able to do this than fathers, who tend to isolate. In a small group, parents can identify with one another and draw strength from knowing that their behaviour is not exceptional, and that their struggles and problems are similar for everyone going through the agony of caring for and supporting a dying child (McCollum, 1974; Satterwhite, Belle-Isle & Conradt, 1978; Fischhoff & O'Brien, 1977; Patten, 1974; Borstein & Klein, 1974; Martinson & Jorgens, 1976).

6.4.3 The Marital Relationship

Throughout the often long and drawn-out terminal illness of the child, the psychologist will have to evaluate the nature and quality of the marital relationship in every session with the family and/or the parents. It may be advisable to see the parents separately on a regular basis, and to deal immediately with conflict and tension in the relationship.

Parents should be seen together. The purpose of this is to help both parents to focus on the common aspects of their plight and develop some practical ways to support each other directly. In order to arrange a joint session with the parents, the psychologist must contact each spouse individually and not extend an invitation to the peripheral parent through the one who is over-involved, thus exacerbating the alienation of the former.

Open communication between parents is of immediate and primary concern to the psychologist. He will be sensitive to any indication of unresolved anger and misunderstood depression, and may encourage the spouses to deal with these in a constructive way. However, the psychologist also realises that open communication may not be possible in all circumstances and that some degree of denial and repression may be needed to allow the parents to function in the crisis of death.

Although society does not allow the parents to give up hope that their children might survive, it is also assumed that they should be grief-stricken. Therefore, parents are not expected to take part in normal social activities or to be interested in any form of entertainment. The relatively long course of terminal illness makes this expectation not only

unrealistic, but undesirable. The psychologist may find himself in a position where he not only encourages parents to take time away from the child, but also gives them "permission" to do so. The psychologist must be careful to ensure that the parents do not sacrifice themselves, their marriage and the rest of the family for the child who is dying. Having confronted their feelings of anger, guilt, fear and grief, they may become free to get away from the hospital at times so that they can continue to maintain and extend their emotional ties and interests outside the hospital, and invest in their marital relationship. Their return to a more normal atmosphere gives them partial relief from the strain and the opportunity to enjoy each other's presence and consolation.

By virtue of their traditional role, mothers are usually more involved in the care of their dying child, which reduces feelings of shame, guilt and isolation. The psychologist can encourage father's participation by including him when the physical and emotional care of the child is discussed. Sharing the time at the bedside will also benefit the marital relationship (Burton, 1974b; Binger, Ablin, Feuerstein, Kushner, Zoger & Mikkelsen, 1969; Krant, 1974b; Easson, 1970).

Having been through the trauma of terminal illness and having survived it with the help of a competent psychologist and with the support of the team, and friends, the marital relationship will have grown and matured.

6.4.4 Parenting the Dying Child

During remissions, when he is at home, the dying child may capitalise on his special status. If he does not get his own way, he may taunt his parents with the idea that he is dying - and how can they treat him

harshly? The psychologist needs to discuss these issues extensively before the child's discharge from hospital. He must support and encourage the parents to deal with their dying child in as healthy and realistic a way as possible.

Depending upon the child's age, the psychologist must help the parents understand what constitutes a happy life for the child who happens to be dying, emphasising the need for love and security without sacrificing discipline. The psychologist must help parents to provide appropriate external controls for the child, since regressive behaviour which is out of control produces anxiety and depression in the child as well as in the parents. Parents must also be advised to refrain from talking incessantly about the illness and from constantly asking the child how he feels. In this way the psychologist can significantly help the parents to modulate their relationship with the dying child, so that their own needs and those of the other siblings are safeguarded. Such intervention requires an interplay between helping the parent understand and endure the emotions which their child's terminal illness arouses, supporting them in modifying their behavioural interaction with the child, and guiding them in utilising all available external resources (McCollum, 1974; Toch, 1972; Gibbons, 1974).

6.4.5 Parenting the Siblings

The psychologist must discuss the needs of the dying child's brothers and sisters with the parents. He may find this difficult because parents may be over-involved with their own needs during the terminal illness of a child, and may therefore find it difficult to understand the siblings'

"uninvolvement" in the tragedy. The psychologist needs to explain that children need to return to what is familiar - toys, friends, home - in order to assimilate what is "terrible" and "unfamiliar". The psychologist needs to be aware of any "emotional blackmail" by the parents, in which they may subconsciously, or even consciously, force children into expressing grief which they do not really feel. Any tendency to continue usual interests and play activities may be frowned upon by parents, in such a way as to make the child feel that he has committed little short of the unpardonable sin.

A danger arises when parents have completed their anticipatory grieving and, suddenly, over-involve themselves in the siblings, expecting one of them to live in the image of the dying child, but simultaneously giving a clear message that he could never really measure up to the saintly image of the child who is dying. The psychologist will have to alert parents to this type of behaviour, as well as to over-protectiveness and other types of restrictions placed on the siblings through fears that something might also happen to them. These fears may become unrealistically exaggerated and may lead to later personality difficulties for the siblings. The psychologist must encourage parents to be honest in their emotional expression, and must explain to them that children feel supported in facing their own fears when they see and feel their parents' ability to experience fully their own grief. If a child is told with feeling about the terminal illness of a brother, he will respond with feeling.

The psychologist should warn parents against sending children away to neighbours or friends during the time of tragedy. Relocation of children at a time of family sadness may intensify their feelings of loneliness and increase the difficulty of their adjustment. Parents must be reminded to

give their children constant reassurance of love, as well as explanations. Even young ones understand more than they are often given credit for.

The parents' continued absence from home may contribute to regressive behaviour as well as disciplinary problems in the family setting. For example, because of their own anxiety, loneliness and at times physical exhaustion, parents may encourage behaviour such as children sleeping in the parental bed, or they may respond to every sound a child makes at night, thus reinforcing regressive behaviour. The psychologist must be alert to such behaviour and encourage parents to communicate reassurance and stability to their children, for example, by saying: "I'm in the room next door and nothing will happen."

Parents may feel guilty about their continued absence from home and the way they neglect the siblings of their dying child. Frequently, their first inclination upon their return home is to compensate the siblings. This could lead to the undermining of the authority of the parent who must try to discipline the children in spite of the tragedy which the family is experiencing. Parents must be encouraged and supported to continue in as normal a manner as possible, and not to avoid their normal parenting functions (Kohn & Kohn, 1978; Goldberg, 1977; Furman, 1970).

6.4.6 Coping with Final Death

Parents may need intensive help when the child is actually dying. At this time, the relationship of trust and respect which has been built over days, weeks or even months, between the psychologist and the parents, may help to ease the acute distress. The child must be helped to die with dignity, and the parents can be spared much grief if attention is given to detail which

may seem small and irrelevant. The room should be kept neat, confusion should be kept to a minimum and there should be little change in personnel. In addition, prompt and kind help should always be available.

In talking to the parents, the psychologist must emphasise that everything medical has been done, and is still being done, for their child. They need to be reassured that the people who have cared for their child until now are not going to give up, but will continue to do their utmost for his general well being.

Parents who have denied the terminal nature of their child's illness may benefit from being helped by the psychologist to face reality. This will enable them to finish unfinished business with the child, and say goodbye. When there is visible physical deterioration, and with the approach of the final days and hours, the psychologist may suggest to the parents that they rehearse the death of their child in the privacy of their own minds, as a way of preparing for the actual event. They can even be encouraged to read the burial services as though death had already occurred, and to plan funeral arrangements. This could help them to accept the inevitable and become free of their own needs, so that they can concern themselves with their dying child.

The psychologist must encourage parents to talk in their normal tone of voice in the death room and not to discuss matters which are not meant for the child's ears, although he may be comatose, as hearing is the last faculty to be lost before death. Whispering and talking in hushed tones creates anxiety in the child, whereas hearing the wellknown and loved voices of family members provides a feeling of safety and security.

Parents may be encouraged to hold their child during the final minutes and they may need to be reassured that they will not, through holding the child, interfere with the process of dying.

Some children may become restless and disorientated. Narcotics, sedatives and tranquillizers may be used whenever necessary, but must always be used judiciously. Parents are able to accept the death of their child with far greater ease when the child is free from pain and appears to be at peace with himself (Toch, 1972; Evans & Edin, 1968; Gyulay, 1977; Weisman, 1977; Bowers, Jackson, Knight & Le Shan, 1964).

In summary, the goal of therapeutic work with the parents of a dying child is to help to strengthen the adaptive capabilities and coping styles specific to each marriage and to each spouse. The parents must be helped to move forward as best they can, with a commitment to enhance the remaining time of the child's life. Furthermore, they must be given access to their own strengths, and to intrafamilial and extrafamilial sources of support, which they will need in order to cope with and emotionally survive the death of their child.

6.5 THERAPEUTIC INTERVENTION WITH SIBLINGS

The psychologist can play a significant role in caring for the siblings of a dying child who are usually sadly neglected by the caring professions and the parents.

The psychologist must use every therapeutic means available, as described in Chapter 4, to help the siblings express their feelings of sadness,

worry, anger and fear. It is important that "death" should not be taboo and the psychologist should be sensitive to any subtle indirect reference to this subject through which the child "tests" whether it is safe to talk about it or not. Talk about the sibling's illness should not only be allowed, but actively encouraged with the illness being explained in simple, not greatly detailed terms. An effort should be made to answer the child's questions as truthfully as possible, in terms consistent with the family's cultural and religious orientation. The child should not be rushed or pushed into communicating these feelings, or to ask any questions. He will do so in his own time, in his own way.

Children need reassurance from the psychologist that the sibling's illness was in no way a result of their own earlier horrible thoughts and wishes towards the sick child, and that their resentment at the attention required by the ill child is understandable.

A child's despair at the possible loss of a loved sibling can lead to anger, which may be vented on others in the form of more frequent fights at school with friends and teachers. Occasionally, a pet belonging to the dying child may be identified with that child and a sibling may express his anger at the sibling's "desertion" by attacking, and possibly even killing, the pet. It seems that by experimenting with death and even inflicting death on an inoffensive creature, the child imagines himself to be the master of life, the conqueror of death. The psychologist can explain to the child that it is natural to become angry when a prized possession is taken away. This may help him to realise that his behaviour is not abnormal, that it should not result in guilt, and that it will pass in time. The psychologist must go out of his way to ensure that the child

does not associate illness and death with sin and punishment, which happens all too often.

The psychologist needs to reassure siblings that the alteration in their parents' moods and behaviour does not reflect a loss of love or interest in them, and that they need not fear that their parents will abandon them. They need reassurance that they are not expected to grieve in the same way as their parents do. They also need reassurance that they will not also develop the illness.

The siblings must be encouraged by the psychologist to visit their ill brother or sister in hospital. This is important in order to prevent their building up fantasies about the ill child. It also enables them to see the hospital in a rather better perspective, and to ask questions themselves.

When there is a fundamental change in the family dynamics, a personal pet may provide a therapeutic haven to the sibling. In his play with the pet, the child may work out his feelings of guilt and fear, and his attempts to atone for the wrongs he believes he has committed. At this time, the psychologist may encourage the introduction into the family of a pet which will be a live companion to the sibling, and will not usually be competition for the parents' attention.

The psychologist must be available to comfort siblings through his words and presence. Often children need to feel the presence of a caring adult rather than hear of it from others (Lindsay & MacCarthy, 1974; Friedman, 1968; Hendin, 1974; McCollum, 1974; Levinson & Kinney, 1974; Feinberg, 1970).

6.6 THERAPEUTIC INTERVENTION WITH SIGNIFICANT OTHERS

6.6.1 Grandparents

The psychologist needs to evaluate carefully the role of the grandparents in the family, and their particular needs. The whole range of emotional reactions displayed by parents can be observed in grandparents. At times, these reactions may be complicated by previous unresolved grief experiences.

The psychologist should devote some of his time and energy to grandparents. He needs to be supportive, but can also point out intrusive and manipulative behaviour on their part. He needs to help them ventilate their feelings in a constructive way. By carefully explaining the facts, and by allaying all the fears created by poor communication between parents and grandparents, the psychologist may help the family, including the grandparents, to face the painful truth and to develop more stable relationships. Once grandparents feel understood and cared for, they can render invaluable assistance to the family in this time of crisis (Gyulay, 1978).

6.6.2 Peers and Friends

Frequently the parents and the neighbours are so concerned with the dying child and the grieving family that they tend to be insensitive to friends and peers of the dying child. The psychologist has a responsibility towards them too as they have just learned what can happen to a child their own age once very much alive like them, but now dying. To grow emotionally and intellectually, these surviving children need to be allowed to think

and talk about death, while still feeling protected. Once in a while, the psychologist should engage in conversation with a friend who comes to visit the dying child and sits in the waiting room. Another possibility is to visit the dying child's class at school, and ask the teacher to talk to the class about what is happening to their friend. The teacher can be used to help the children verbalise their anxiety, sadness and fears, through both expressive and creative art. In this way, the sensitive teacher may play an invaluable role in supporting, reassuring and caring for the child's friends and peers. Whenever she feels especially concerned about one of her class members, she may refer the child to the psychologist.

6.7 CONCLUDING REMARKS

In this chapter, different approaches to and therapeutic interventions with the family which is in the process of losing a child through death, have been discussed. They need the involvement of the clinical psychologist who can effectively work with the family as a whole, with individual subsystems and with the individual members of the family, as well as with peers and friends of the dying child.

Caring for the dying child should always involve caring for the family, because the child will benefit greatly from any investment in the family. It may be a costly endeavour in terms of energy and time, but the price of a "good death" can perhaps never be calculated. In modern medicine, prevention is the goal. This is also true of the involvement of the clinical psychologist with the family, which may be seen as preventative in terms of the trauma of grief and loss which the family must successfully negotiate in order to continue functioning effectively.

CHAPTER 7

CONCLUDING COMMENTS

On the basis of the discussion within this thesis, the following conclusions can be drawn:

1. The care of dying children is demanding and often inadequate due to lack of knowledge and insight on the part of the treatment team.

The needs of the dying child are diverse and complex. In order to help, support and interact meaningfully with the dying child, it is important to enter the world of the child's perceptions, thoughts and feelings, and to approach the child from a position of equality and respect. However, adults seem to find it difficult to grant personhood to a child, resulting in their addressing the child from a position of superiority. The care of the dying child presents the family and the professional helpers with one of the greatest management tasks. People wanting to work with dying children need a basic understanding of child development, including the development of the concept of death. They also need knowledge about cultural and religious attitudes and customs. Basic counselling skills, honesty and integrity are essential, as well as sensitivity to problems of communication experienced at different ages. Few people in the helping profession seem to have all these qualities, and training of professionals in caring for the dying child, therefore, should be a priority.

2. The interdisciplinary team who accepts responsibility for caring for the dying child is incomplete without the clinical psychologist.

It is clear that the clinical psychologist with his specialised theoretical and clinical training in human behaviour possesses skills

which are indispensable to the effective functioning of the team. The clinical psychologist can assist the dying child to live through the process of dying and to appreciate the fullest meaning of life itself. Serious consideration must be given to the incorporation of a course of thanatology in the training programme of students in clinical psychology. Practising clinical psychologists could be stimulated in their thinking and assisted through workshops and lectures, in acquiring the necessary skills to engage therapeutically with dying children. More interest in this area will lead to an increase in research and publications which are urgently required.

The only way to create a need for a clinical psychologist as a member of the medical team caring for the dying child is for competent clinical psychologists to offer efficient professional service.

3. Neglect of the family complicates the dying trajectory of the child and increases the risk of pathology within the family.

Currently, increased emphasis is being placed upon preventative medicine. Preventative medicine also means adequate terminal care. This seems contradictory, but caring for parents and siblings in their anticipatory grief and post-death bereavement will benefit the dying child who needs an environment of security and safety. It will also enable family members to return to the mainstream of life after the death of the child, and to resume their responsibilities within a shorter time.

4. Each member of the team who cares for the dying child needs support.

Caring for the dying child is a physically exhausting and emotionally taxing experience. The clinical psychologist can play a most important role as a support for the front-line care givers. He should not only play a part in organising and maintaining a high standard of psychological care and in teaching medical staff, but should also provide individual support to staff members who find it difficult to cope with their responsibilities. Terminal care is a matter of human relationships. The clinical psychologist can learn skills and insights from text books and even from patients themselves, but caring for a dying child demands that the whole of himself be available to relate to another human being - the child who is dying. This could leave the clinical psychologist exposed and vulnerable and, therefore, he too needs support and stimulation through individual therapy, consultation and supervision.

5. Our death-denying society exposes children to violent death on television and in popular magazines, but provides no opportunity for children to deal with their fears and fantasies about death and dying. As a result, they find themselves isolated and alone when a friend, a sibling, or a member of the family becomes terminally ill or dies suddenly.

Teachers who spend an average of five hours a day with children in their class are often ill-equipped to cope with, understand and support a grieving child, or a child who is suffering from a terminal disease and who, over months and even years, may continue to attend school during periods of remission. There is a strong case for the Departments of Education to make provision for this as a part of teacher training.

In conclusion, it is necessary that the whole area of caring for the dying child and the family should be reappraised, and further attempts should be made to facilitate better care and understanding.

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